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ABSTRACT

Interviews were conducted with 32 American Indians with disabilities in Cibola, McKinley, and San Juan counties, New Mexico. The study sought to identify the needs of northwest New Mexico American Indians with disabilities with regard to independently carrying out daily living activities. With an average age of 49, interviewees frequently reported blindness, hearing impairments, and hypertension as disabling conditions. The most numerous tribal affiliation was Navajo (75 percent), followed by Zuni and Laguna. Interviewees described their experiences with services needed and received in the past year. A lack of knowledge about services was one of the most common barriers to receiving services. Of 32 responses regarding personal assistance services, 23 interviewees indicated that someone, usually a family member, assisted them with daily activities. Interviewees' most important concerns were service providers' involvement of family members and extended family members in rehabilitation services, the need to feel safe in home and neighborhood, the desire for the Indian community to understand its disabled members' needs, and the need for information about legal rights and self-advocacy. Two community meetings were held to review preliminary findings. Community concerns included funding needs of community-based consumers and service providers, access to cultural activities, and lack of action by tribal leaders. Includes recommendations to state and tribal agencies and the interview instrument. (Author/SV)

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Independent Living Outcomes for American Indians with Disabilities:

A Needs Assessment of American Indians with Disabilities in Northwest New Mexico

Cibola and McKinley Counties

1996

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American Indian Rehabilitation Research and Training Center

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CIRCLES
August 1993

**You are a very strong person
When you come up to a wall
and recognize the wall overcome it.**

**These are called circles, some circles
are stronger and some are there
to slow you down, so you will not
miss the things you need to know.**

**Before you get over that wall
another one pops up and that one is
another circle you have to overcome.**

This is your life cycle.

**Some people only climb
a few walls and give up.
These people are trapped
and have nowhere to go
so they go the same route
year to year.**

**The best thing to do is overcome
the walls, not go through them.**

**Because if you go through it,
parts of it are still there and,
they resurface sometime in the future.**

Overcome it and, it is gone forever.

STRAIGHT ARROW

**Mr. Ronald Sam (Athabaskan)
Research Project Advisory Committee Member and
AIRRTC National Advisory Board Member
Passed on August 14, 1995**

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This study would not have been possible without the assistance of individuals and organizations who care and want to improve the lives of American Indians with disabilities and their families. The hard work and enthusiasm of the New Mexico research technician, Ms. Tonilisa Nezz (Navajo) is greatly appreciated; without her support, the New Mexico interviews would not have been completed. We also extend our appreciation to the American Indians with disabilities who were interviewed by Ms. Nezz and to those who provided referrals for Ms. Nezz to interview.

Several people in New Mexico assisted in identifying American Indians with disabilities who were potential interviewees. Ms. Lela Goldsmith, Public Health Nurse in Ramah, Mr. Chris Luther, consumer advocate in Laguna, and Ms. Ela Yazzie-King, Indian Children's Program, were helpful in coordinating contacts for Tonilisa.

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Many thanks to the individuals who spent time at the initial meeting in Albuquerque on December 15, 1994 in identifying consumer concerns. As a result of that meeting, the initial draft of the consumer interview questionnaire was developed for the state of New Mexico. Both Mr. Chris Luther (Laguna), a member of the American Indian Rehabilitation Research and Training Center's (AIRRTC) advisory board and research Project Advisory Committee and Mr. Eldon Francisco reviewed the consumer interview questionnaire and offered feedback to the research team. We are grateful for their input and time.

And many thanks to the people who attended the Ramah and Crownpoint community meetings in New Mexico. These people provided their input and recommendations for the preliminary report.

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Summary

This report examines and discusses the needs identified in interviews by American Indians with disabilities in northwest New Mexico. The identification of needs is usually a first step in determining recommendations for key stakeholders so they can address those needs. Key stakeholders in this study are the American Indians with disabilities and their family/extended family, New Mexico Division of Vocational Rehabilitation, Navajo Nation Office of Special Education and Rehabilitation Services, Community Health Representatives, Indian Health Service, local Chapter House officials on the Navajo reservation, the Navajo President and council delegates, New Mexico Centers for Independent Living, New Mexico Statewide Independent Living Council, New Mexico State Rehabilitation Advisory Council, and the federal Rehabilitation Services Administration.

Documenting the needs of American Indians with disabilities assures policy makers and funding agencies that assistance in service provision, outreach services, and maintaining and increasing program funding is needed. The purpose of this study was to understand the needs of northwest New Mexico American Indians with disabilities who may have problems that limit their ability to independently carry out daily activities such as walking, talking, cooking, eating, bathing, or shopping.

Thirty-two American Indians with disabilities were interviewed in three counties (Cibola, McKinley, and San Juan). Originally, the intent of the project was not to primarily focus in a specific area in the state; however, referrals given to the on-site coordinator turned out to be mainly from three counties in New Mexico. The data analysis consisted primarily of a descriptive summary of quantitative data.

The research project on-site coordinator conducted the interviews by asking questions (see Appendix B) and marking the answers on the questionnaire. At appropriate times, a flash card was shown to the interviewee. For example, a

question was asked regarding what type of services were needed in the past year but not received.

The average age of the New Mexico interviewees was 49 years. The interviewees frequently reported blindness, hearing impairment, and hypertension as disabling conditions. The interviewees reported a lack of knowledge about services as one of the most common barriers to receiving services. Some of these services were help with service coordination, help with food, dental care, help with housing, job help, medical care, eye/vision care, how to cook, clean, or shop, counseling, and help with alcohol abuse.

Of the 32 responses regarding personal assistance services, 23 indicated that they have a person that assists them in their daily activities. Almost half of these interviewees reported that their family members (22) were helping them in their daily living.

The interviewees top five concerns in order of importance were: (1) social service providers should involve family members and extended family members in their rehabilitation; (2) you should feel safe in your home and neighborhood; (3) the Indian community understands the needs of its members with disabilities; and (4) information about legal rights and self-advocacy is available to American Indians with disabilities.

Two community meetings were conducted to review the preliminary report of this study. The overall concerns from the community were: (a) funding for community-based consumers and service providers, (b) access to cultural activities, and (c) tribal leaders not addressing the needs of tribal members with disabilities.

A Needs Assessment of American Indians with Disabilities in Northwest New Mexico

The purpose of this study was to understand the needs of American Indians with disabilities who may have problems that limit their ability to independently carry out daily activities, such as walking, talking, cooking, eating, bathing, or shopping. This report discusses the American Indians with disabilities interviews that were conducted in northwest New Mexico.

Summary information on the number of American Indians and Alaska Natives served by Centers for Independent Living (CIL) as reported by the national data file (704-94) with Rehabilitation Services Administration, Independent Living Branch revealed that the state of New Mexico served 48 American Indians/Alaska Natives with Part II of the Title VII, Independent Living Rehabilitation Services state program, and 11 American Indians/Alaska Natives were served by Part III, Title VII, Centers for Independent Living (CILs). The American Indians/Alaska Natives served in the state of New Mexico in 1994 by CIL as reported by the national data file (704-94) was 59 (.03%). The total served (all general population) was 1,193 (.08%) in New Mexico. In other words, in New Mexico, the rate of independent living service delivery for the general population is much higher than the service rate for American Indians and Alaska Natives. Caution should be taken in interpreting these data because American Indian/Alaska Native heritage claims are defined and solicited on a voluntary basis. This means that counts may be *minimums*, or over-counts because counts are voluntary and optional.

Methodology

Client information was collected using an interview instrument based on the consumer concerns report method developed by the University of Kansas Independent Living Center (Fawcett, Suarez de Balcazar, Whang-Ramos, Seekins, Bradford, & Mathews, 1988). Ms. Lela Goldsmith, Public Health Nurse in Ramah, Mr. Chris Luther, consumer advocate on the Laguna reservation, and Ms. Ela Yazzie-King, Indian Children's Program on the Navajo reservation, assisted by identifying New Mexico American Indians with disabilities to be interviewed.

Research Technician

A flier to recruit a research technician was disseminated to state and tribal agencies and at the March, 1995 *Native American Rehabilitation National Conference* in Albuquerque. The research technician's job description specified recruiting and conducting 35 interviews with American Indians with significant disabilities (Appendix A). Ms. Tonilisa Nezz (Navajo) was hired within a couple of weeks after the conference. Ms. Nezz was then trained to conduct interviews according to the "New Mexico Independent Living Concerns of American Indians with Disabilities Needs Assessment," (Appendix B) at the American Indian Rehabilitation Research and Training Center (AIRRTC) office in Flagstaff, Arizona.

Definition Used for Severe Disability

The criterion for interviewees, who were American Indians with disabilities, was that they had to be severely disabled. The definition used for severe disability was:

A severe physical or mental impairment which substantially limits a person's ability to function independently in the family or community or which substantially limits a person's ability to obtain, maintain, or advance in employment and which can be improved when independent living services are provided.

Designing the Interview Instrument

The interview instrument included seven sections adapted from previous projects (Marshall, Day-Davila, & Mackin, 1992; Marshall, Johnson, Martin, Jr., & Saravanabhavan, 1993; Schacht, Hickman, Klibaner, & Jordan, 1993; Schacht, Morris, & Gaseoma, 1993): general information, disability information, services information (formal support systems), educational information, employment information, social information, and conclusions. To these, two new sections were added, one on medical rehabilitation facilities and another on personal assistance services. Also, the services information section was expanded to include several pages of questions on independent living services. A tenth section, consumer concerns, was developed by New Mexico, Arizona, and South Dakota focus groups, and is described separately below.

Consumer Concerns. On August 31, 1994 the research team met with Franklin Halwood (Navajo), an AIRRTC data entry operator with a severe disability to select 60 issue statements from 173 Statements for the working groups. A tentative list of issue statements that Mr. Halwood was asked were:

(a) How important is it to you that...

(b) How satisfied are you that...

- you have the same opportunity as any other citizen to participate in your community.
- support and help are available from community members.
- the Indian community understands the needs of its members with disabilities.
- you are not isolated from your friends and neighbors because of your disability.
- people with disabilities in the Indian community communicate with each other.

They also considered issue statements identified by the surveys conducted by AIRRTC in Denver (Marshall, Johnson, Martin, Jr., & Saravanabhavan, 1993), Minneapolis-St. Paul (Marshall, Day-Davila, & Mackin, 1992), Dallas-Ft. Worth (Schacht, Hickman, Klibaner, & Jordan, 1993), and Houston (Schacht, Morris, & Gaseoma, 1993). The principal investigator then made an additional list of statements with a stronger emphasis on independent living issues.

(a) How important is it to you that...

(b) How satisfied are you that...

- dirt or gravel paths and driveways are smoothed periodically.
- tribal buildings are accessible to Native people with disabilities.
- the medicine man is a member of the medical rehabilitation team.
- your tribal government is informed about ADA (Americans with Disabilities Act) and how you can adopt such a legislation on your reservation.
- tribal vocational rehabilitation/independent living services is responsible to the needs of American Indians with disabilities.

The resulting 60 statements were presented to the working groups in the target states of New Mexico, Arizona, and South Dakota. The groups used these statements as a guideline to determine which were most important to them. Their responses were tallied, the statements receiving the most votes were discussed and revised and the group agreed upon which statements to include.

The New Mexico working group considered the 60 statements used in the Arizona and South Dakota working groups (Lansing-Sanderson & Schacht, 1994). Most of the statements were discussed, and 25 were chosen. The members voted on whether to add, delete, or reword each statement. Any new information agreed upon was changed on the overhead and noted. The wording for three issue statements was changed as a result of the discussion. The New Mexico working

group decided to use "American Indian" rather than "Native American" in the consumer concerns section. Additionally, 12 new statements were suggested by individuals advocating for their clients, and these were placed in "consumer concerns" format. Some of these issue statements and their precise wording were not discussed or voted upon due to a lack of time. These consumer concerns were then compiled and sent to two consumers, Chris Luther (Laguna) and Eldon Francisco (Laguna), both from Laguna Pueblo village, for their review. They were consulted by telephone conference to finish the work of the Albuquerque working group. After revising the consumer concerns in light of their suggestions, the "Independent Living Concerns of American Indians with Disabilities Needs Assessment, Consumer Pilot Interview, New Mexico," was completed on March 6, 1995 (see Appendix B) and was ready for a field test.

Personal Assistance Services

On September 2, 1994, Dr. Lance Egley with the Research and Training Center on Personal Assistance Services (RTC-PAS) of the World Institute on Disability (WID) contacted the research team to propose a collaborative research effort that would involve adding a one-page questionnaire on personal assistance services to the "Independent Living Concerns of American Indians with Disabilities Needs Assessment" for New Mexico, Arizona, and South Dakota. That day, Dr. Egley faxed the interview questions about personal assistance for American Indian people, his project abstract, and other research project abstracts from his grant. Dr. Egley asked the research team to review the interview questions and offer feedback to him. Apparently, Dr. Egley was already working with the Navajo Nation Office of Special Education and Rehabilitation Services (Navajo Nation OSERS), a Section 130 vocational rehabilitation program that has an independent living program. Dr. Egley, with the assistance from the Navajo Nation OSERS, developed questions related to personal assistance services and copies of the "Questions about Personal

Assistance to Explore at the Navajo Nation," "Questions for Institutions and Health Providers on the Navajo Nation," and Questions to Ask Community Health Representatives (or Community Health Nurses)" were faxed to the research team for their review and input. The RTC-PAS of WID defines personal assistance as:

One human being assists another person with a disability to do something the person with a disability could not do for himself/herself. People get assistance with various things. A few examples are getting in or out of bed, dressing, eating, bathing, cooking, shopping, laundry, transportation, or reading. Personal assistance has been a useful resource for people with disabilities to help realize their rights. Different people get assistance in different ways and some ways work better for certain people.

Dr. Egley met with the research team on October 31, 1994, to discuss the questionnaires that he faxed and to review his project goals. The research team agreed that personal assistance services were one of the greatest needs on Indian lands, and that the need for an American Indian personal assistant as a caregiver was essential. Personal assistance enables an individual to live independently. Personal care is usually provided by family members in Indian communities; thus, the terminology "personal assistance services" is new to Indian country. The research team decided to collaborate with WID to enhance information for the independent living research project conducted by AIRRTC. After the meeting with Dr. Egley, a questionnaire consisting of 14 questions related to personal assistance services was developed and inserted into the needs assessment for New Mexico, Arizona and South Dakota. On December 13, 1994, a list of personal assistance services was sent by Dr. Egley to the AIRRTC research technicians that described the range and scope of PAS. The intent was to help the research technicians in explaining what PAS means if a respondent inquired.

An agreement between the WID and AIRRTC research team at Northern Arizona University provided compensation for the extra time and effort required by adding one page of WID questions on personal assistance services (PAS) to the AIRRTC interviews of American Indians with disabilities. This included time taken during interviews to read the questions and write their open-ended responses, as well as time taken after the interviews to affix respondent identification to the PAS page of questions, detach it from the interview questionnaire, and mail these pages of PAS questions to WID for analysis. Additionally, the research team recommended that Dr. Egley hire an American Indian consultant to work on his research project on PAS for American Indians. A flier on January 17, 1995 to recruit for this position was sent to the AIRRTC research team for dissemination.

Working Group

A consumer working group meeting was held in Albuquerque, New Mexico on December 15, 1994, with the help of the American Indian Vocational Rehabilitation Project, with the New Mexico Division of Vocational Rehabilitation. This group identified problems and concerns during the meeting that were used to develop a questionnaire to interview consumers in New Mexico. Unfortunately, the working group had only one American Indian with a disability and that person left before the meeting began due to a misunderstanding. Another reason for the absence of consumers may have been the lack of mileage money from the AIRRTC for out-of-town participants. The rest of the working group members were service providers and advocates from Pueblo tribes, mostly rehabilitation technicians. Communication regarding recruiting American Indians with disabilities to participate in the meeting had somehow been misunderstood, although the service providers gave good input on their consumer's needs in New Mexico. At the request of the working group, a tape recorder was not used to record the discussion during the meeting.

Conducting the Survey

Ms. Tonilisa Nezz, AIRRTC research technician, was responsible for all New Mexico project activities, including meeting with project staff to review interviewing procedures, recruiting people to be interviewed, interviewing the people, explaining the purpose of the interview and making appointments for interviews, obtaining signatures on informed consent forms from the persons to be interviewed, traveling to homes of interviewees or other mutually agreeable sites to conduct interviews; completing all paperwork relating to interviews such as invoice payment, excess travel expenses, processing contact logs, recording interviews completed, mileage, billing statements, and routing the completed questionnaires and other relevant paperwork to the co-principal investigator at the AIRRTC office at Northern Arizona University. Ms. Nezz also participated in monthly research meetings to report her activities and weekly reports to the co-principal investigator. After the interviews were completed, Ms. Nezz located meeting rooms and facilities for the two community meetings in New Mexico. Ms. Nezz also coordinated lunch and developed a list of people to be invited to the community meetings in New Mexico.

Recruiting Interviews

A flier was disseminated to service providers on the Navajo reservation and Laguna and Zuni Pueblo villages by Ms. Nezz (Appendix C). The flier, "Explaining the Study" recruited American Indians with disabilities to be interviewed and asked what problems are most important to consumers.

Billing and Data Entry

The co-investigator verified information received, such as billing forms and contact logs, from the research technician. Interviewees received \$20 for their time and effort. The interviewer also received compensation for interviewing, mileage traveled, and other relevant expenses. The data from the questionnaires was then

entered into a computer for analysis using the "Q & A for Windows" software package, Version 4 (Symantec Corporation, 1993).

Community Meetings

Two community meetings were conducted in New Mexico on January 25, 1996 in Ramah and January 26, 1996 in Crownpoint. Both of these meetings were located on the Navajo reservation. The purpose of the meetings was to discuss the preliminary draft of this report to obtain feedback and recommendations from American Indian consumers (especially those who had been interviewed), and service providers present at the meeting(s); the agenda for the meetings can be found in Appendix D.

Ms. Tonilisa Nezz arranged the meeting locations. Since there are no street addresses in Crownpoint and Ramah, Ms. Nezz developed maps to send with the invitations showing how to get to both meeting sites, disseminated the meeting agenda and maps to American Indians with disabilities who participated in the interviews, family members, service providers, and tribal leaders. She also arranged for Navajo interpreters to interpret during the meetings.

Approximately 40 people attended the meeting in Ramah including American Indians with disabilities who had participated in the interviews, family members, New Mexico Division of Vocational Rehabilitation Services service providers, Navajo Nation Office of Special Education Rehabilitation Services independent living counselors, and Ramah community members. The meeting was conducted at the Ramah Chapter House, a central meeting place for local community gatherings.

After receiving permission to record the meeting, two tape recorders were left on throughout the meeting. The general theme of the meeting was the problem on accessing resources to meet the need of American Indians with disabilities and

providing rehabilitation services. Comments by some participants are included in the results section.

Approximately 20 participants attended the Crownpoint meeting. A majority of the participants were elderly Navajo residents of the Elderly Home Care Center, where the meeting was held. Other consumers present included consumers in wheelchairs and consumers using oxygen. Service providers represented included: the New Mexico Commission for the Blind, Toyei Industries, Tohatchi Special Education and Training Center, Navajo Nation Office of Special Education Rehabilitation Service (NNOSERS) programs (Independent Living, Vocational Rehabilitation, and Early Intervention), and the Laguna Center for Independent Living. The NNOSERS independent living counselors and the Laguna Center for Independent Living service providers attended both community meetings in Ramah and Crownpoint.

A Navajo interpreter interpreted the information into Navajo with some assistance from the Navajo OSERS staff. The participants discussed their attempts to advocate on meeting their needs by informing service providers and tribal leaders. An administrator present at the meeting provided an explanation into the process of purchasing aids and devices and grant approval process. Several consumers present requested for independent living services, and the service providers made arrangements to meet with them later.

Results

Distribution of Interviews

Thirty-two American Indians with disabilities were interviewed in three counties in northwestern New Mexico (see Table 1). Of these, 53% were in Cibola County in Pine Hill, Ramah, Laguna, and Sunset Village, of which interviewees were mostly in Pine Hill or Ramah. Another 44% were in McKinley County,

Table 1 Summary of Respondent Addresses, by County			
	American Indian Population	Interviews	
County	(1990)	N	%
Cibola	9,153	17	53%
McKinley	43,549	14	44%
San Juan	33,613	1	3%
All NM Reservations	87,876	32	100%

in Zuni, Crownpoint, Thoreau, Gallup, Borrego Pass, Manuelito, Prewitt, and Vanderwagon. One interviewee was from Kirtland in San Juan County. Parts of the Navajo and Zuni reservations are in these counties.

Characteristics of Respondents

Most [18 (56%)] of the respondents were male. The respondents ranged in age from 22 to 85, but 75% were between 22 and 60 years of age. The average age was 49 years.

The most numerous tribal affiliation (see Table 2) was Navajo (75%). Other tribes included Zuni (13%) and Laguna (6%).

Since the term disability is itself not universally known or understood in the same way, respondents were asked a series of questions that looked at disability from different perspectives. First, respondents were asked to describe their condition, long-term illness, handicap(s), disability, or disabilities. The results are listed in Table 3. The most common disability was blindness [9 (28%)]. Hearing impairment and hypertension were also common [7 (22%) each]. Many respondents had more

Table 2 Tribal Affiliation of Respondents	
Tribal Affiliation	Total N
Navajo	24
Zuni	4
Laguna	2
No response	2
Total	32

than one disability; in fact, the respondents had an average of about two (2.2) disabilities each.

Respondents were then asked about things they used or needed because of their disability. Most [19 (59%)] indicated that they used medications. Almost as many [17 (53%)] said they use eyeglasses or contact lenses, and many [11 (34%)] said they needed improved eyeglasses or contacts. Six respondents (19%) used hearing aids, and five (16%) said they needed improved hearing aids. Most of the people who had eyeglasses or contacts, hearing aids, or wheelchairs or scooters needed improvements in these things. In general, most respondents had the disability aids and devices they needed, but most needed improvements in their aid or device. These and the other disability aids and devices are shown in Table 4.

Respondents were also asked what activities are limited by their disability or disabilities (see Table 5). The three most common responses were "Working on a job" [22 (69%)], "Taking care of things/responsibilities" [21 (66%)], and "Driving" [20 (63%)]. "Working around controlled substances" was reported by one respondent

Table 3
Disabilities

Disability	Frequency	Percentage of 32
Blindness	9	28%
Hearing impairment	7	22%
Hypertension (High Blood Pressure)	7	22%
Arthritis, chronic arthritis	6	19%
Visual Impairment, low vision, or partially blind	6	19%
Diabetes	4	13%
Heart problems	4	13%
Lung disorder or disease	4	13%
Spinal cord disability, paraplegia, or quadriplegia	4	13%
Eating disorder	2	6%
Mental retardation	2	6%
Orthopedic disorder	2	6%
Specific learning disability	2	6%
Traumatic brain injury	2	6%
Amputation	1	3%
Epilepsy	1	3%
Kidney disorder	1	3%
Polio	1	3%
Stroke	1	3%
Can't use right side of body	1	3%
Car accident	1	3%
Minimum hand coordination	1	3%
Wheel chair/car accident	1	3%
Total	71*	
*Total is greater than 32 because some individuals have more than one disability.		

Table 4						
Assistive Aids and Devices						
Assistive Aids/Devices	Used Currently	Pct. (%)	Needed (if not using)	Pct. (%)	Needs Improvement (if used)	Pct. (%)
Medications	19	59%	1	3%	1	3%
Eyeglasses/contacts	17	53%	2	6%	11	34%
Wheelchair or scooter Manual---10 Electric-----3 Scooter-----1	10	31%	0		8	25%
Walking stick or cane	9	28%	2	6%	4	13%
Walker	8	25%	2	6%	3	9%
Hearing aid	6	19%	0		5	16%
Crutch(es)	4	13%	0		2	6%
Modified vehicle/van	3	9%	1	3%	2	6%
Prosthesis/brace	3	9%	0		1	3%
Magnifying lens/ telescope	2	6%	0		1	3%
Long (white) cane	2	6%	0		1	3%
Lip reading	2	6%	0		0	
Indian medicine	2	6%	0		0	
Braille	1	3%	0		0	
Sign language with fingers	1	3%	0		0	

Table 5
Activity Limitations Due to Disability

Disability Limitations	No Limitations	Yes or Sometimes	Percent 'Yes'
Working on a job	10	22	69%
Taking care of things/responsibilities	10	21	66%
Driving	12	20	63%
Performing manual tasks	14	18	56%
Self-care at home	16	15	47%
Writing	18	14	44%
Walking	18	14	44%
Lifting	19	13	41%
Seeing	20	12	38%
Standing	20	12	38%
Reading	21	11	34%
Use of hands	21	11	34%
Using public transportation	18	11	34%
Use of arms	23	9	28%
Remembering	24	8	25%
Breathing	24	8	25%
Sleeping	25	7	22%
Hearing	26	6	19%
Sitting	26	6	19%
Learning	27	5	16%
Speaking	29	3	9%
Getting along with people	28	2	6%
Working around controlled substances	30	1	3%

as an activity limitation due to a disability. Controlled substances is interpreted as working in a pharmacy.

Experience with Services

Respondents were asked to describe their experiences with services over the past year. The results revealed that what was most needed but not received was service help [21 (66%)] ("Has anyone helped you with services or put you in touch with those who could help you?"), and help with food [19 (59%)] (see Table 6). The most common barrier to receiving services was lack of knowledge about the services. The top five services needed but not received were services coordination, help with food, dental care, help with clothing, and housing help. These top five needs are basic necessities.

Respondents were also asked about the services they were currently receiving (see Table 7, listed in descending order of frequency). They were presented with a list, and responded "yes" or "no" to each item. The three most common service agencies were the Social Security Administration, Indian Health Agency, and Medicare/ Medicaid. Several health service agencies ranked high (Indian Health Agency, Public Health Nurses, Eye Doctor, Community Health Representatives), so that in the aggregate, health services were the primary current service. The most frequent service locations were Gallup and Zuni with the largest number of providers located in Zuni. Indian Health Service (IHS) locations were mostly referred to as PHS (Public Health Service) facilities; at least four PHS facilities were mentioned without a city name. One of the senior citizens programs was located in Mt. View, which was mentioned by five respondents.

Consumer Concerns

The consumer concerns questions were at the heart of the survey. These are the issues that were selected by the working group of consumer advocates from northern New Mexico who met in Albuquerque in December, 1994, and in

Table 6
Services Needed in Past Year but Not Received

Service	Interviewees Needing but Not Receiving		Barriers		Barrier
	N	%	N	%	
Help with services	21	66%	7	22%	Did not know of service
			6	19%	The services were not offered to me
			6	19%	I had no way of getting to the service
Help with food	19	59%	5	16%	Did not know of service
			5	16%	The services were not offered to me
			4	13%	The hours were not convenient
			3	9%	I had no way of getting to the service
Dental care	17	53%	4	13%	The services were not offered to me
			3	9%	Did not know of service
Help with clothing	17	53%	6	19%	The services were not offered to me
			3	9%	I had no way of getting to the service
			3	9%	The hours were not convenient
Help with housing	16	50%	8	25%	Did not know of service
			4	13%	The services were not offered to me
Job help	15	47%	4	13%	Did not know of service
Medical care	14	44%	3	9%	Did not know of service
Eye/vision care	12	38%	4	13%	The hours were not convenient
			3	9%	Did not know of service
			3	9%	I could not afford to use the service
Help with benefits	10	31%	3	9%	Agency personnel were not sensitive to my needs
Special transportation	10	31%	3	9%	The services were not offered to me
How to cook, clean or shop	7	22%	3	9%	Did not know of service
Counseling	6	19%	3	9%	Did not know of service
Help with alcohol abuse	3	9%	3	9%	Did not know of service

Table 7

Most Common Locations of Services Currently Received

Service Provider	Yes #	Gallup	Zuni	Pine Hill	Crown-point	Ramah	Albuquerque	Other
Social Security Administration	25	21	1				2	1
Indian Health Agency	25	3	5	1	5			11
Medicare/Medicaid	23	14	5	2	1			1
Public Health Nurse	15	1	2	10	1			1
Eye Doctor	13	5	4	3			1	
Senior Citizens Program	13				5	3		5
Your Church	13		2	4		2		4
Indian Medicine	10				1	2		5
Community Health Reps	7		1	3	2			1
State Job Service Program	4		2		2			
Medical Rehab Facility /Center	4		2				1	1
Private Medical Doctor	3						3	
Tribal Vocational Rehab	3		3					
Psychologist	2		1				1	
State Div. Vocational Rehab	2		2					
Veterans Affairs Admin.	2						2	
Other	2							
Independent Living Center	1		1					
State Div. of Social Services	1							1
Sweat Lodge	1		1					
Totals		44	32	23	17	7	10	31

consultation with several other New Mexico consumers in telephone conferences. Issue statements covered such subjects as health, social services, transportation, housing, attendant and housekeeping services, public services and government, media, education, employment, counseling, and advocacy. The responses were on a scale from 0 to 4, where 4 represents *very important* or *very satisfied*. For each issue statement, they were first asked how *important* it was to them, and then they were asked how *satisfied* they were with it. Statements that were high in both importance and satisfaction can be considered as relative strengths; the ten top relative strengths are listed in Table 8. A relative strength index was calculated as the harmonic mean of the average importance and average satisfaction of each item. For two items, the harmonic mean is the square root of the product of the two items. In other words, the Relative Strength is equal to the square root of the product of Importance times Satisfaction.

$$\text{Relative Strength} = \sqrt{(\text{Importance}) \times (\text{Satisfaction})}$$

Statements that are high in importance but *low* in satisfaction can be considered as relative problems; the top ten relative problems are listed in Table 9. A relative problem index was calculated as the harmonic mean of the importance, and satisfaction subtracted from 4:

$$\text{Relative Problem} = \sqrt{(\text{Importance}) \times (4 - \text{Satisfaction})}$$

Here, the satisfaction score is subtracted from 4 because the lower the satisfaction, the greater the problem. It is readily apparent from these results that virtually all of the statements are considered very important (scores are 3.5 or

Table 8

New Mexico Consumer Concerns in Descending Order of *Strength* Index

Rank	Item	Concern	Importance		Satisfaction		Strength Index
			N	Mean	N	Mean	
		Maximum:	31	4.00	31	4.00	4.00
1	5	You feel safe in your home and neighborhood.	31	3.71	31	2.52	3.06
2	6	You can call for and get help in an emergency.	30	3.67	28	2.46	3.00
3	7	Affordable housing (both public and private) is available and accessible to people with all types of disabilities.	30	3.57	31	2.45	2.96
4	26	Counselor's work with consumers to find the right assistive or adaptive devices to help them function better.	31	3.61	31	2.32	2.89
5	2	Your family members understand your disability and how to help you function more effectively.	31	3.42	31	2.45	2.89
6	23	Social service providers involve family members and extended family members in your rehabilitation.	31	3.77	31	2.19	2.87
7	19	You have help getting a job in your community	31	3.58	31	2.16	2.78
8	12	Good mental health care is available to American Indians with disabilities.	30	3.50	29	2.17	2.76
9	18	State and tribal vocational rehabilitation agencies provide self-employment opportunities to American Indians with disabilities on reservations.	31	3.48	31	2.19	2.76
10	9	Tribal buildings are accessible to native people with disabilities.	30	3.47	30	2.20	2.76

Importance	Satisfaction
0 = Of no concern to me	0 = Very dissatisfied
1 = Not important	1 = Dissatisfied
2 = Somewhat important	2 = Somewhat satisfied
3 = Important	3 = Satisfied
4 = Very important	4 = Very satisfied

$$\text{Relative Strength} = \sqrt{(\text{imp.}) \times (\text{sat.})}$$

Table 9

New Mexico Consumer Concerns in Descending Order of *Problem* Index

Rank	Item	Concern	Importance		Satisfaction		Problem Index
			N	Mean	N	Mean	
		Maximum:	31	4.00	31	4.00	4.00
1	3	Portable accessible bathrooms are made available at pow-wows and other native social/ traditional gatherings.	31	3.61	31	1.61	2.94
2	24	Assistive devices (such as wheel chairs, braces, hearing aids, and so on) are available and affordable.	31	3.61	31	1.77	2.84
3	8	Your tribal govt. and public services respond to the needs of American Indians with disabilities.	31	3.35	30	1.73	2.76
4	11	Public transportation to shopping, medical, and recreation centers is available to people with disabilities.	30	3.47	31	1.81	2.76
5	1	The Indian community understands the needs of its members with disabilities.	31	3.68	31	1.94	2.75
6	25	Financial assistance for examination and reasonably priced assistive and high tech devices...are available to American Indians with disabilities.	31	3.61	31	1.90	2.75
7	28	Information about legal rights and self-advocacy is available to American Indians with disabilities.	31	3.68	30	1.97	2.73
8	20	Social agencies inform you about benefits and services for which you qualify.	31	3.52	31	1.90	2.72
9	22	ILCs provide IL services on reservations.	31	3.58	30	1.93	2.72
10	10	Tribal and state agencies work together effectively to provide services for American Indians with disabilities.	31	3.61	30	2.00	2.69

Importance	Satisfaction
0 = Of no concern to me	0 = Very dissatisfied
1 = Not important	1 = Dissatisfied
2 = Somewhat important	2 = Somewhat satisfied
3 = Important	3 = Satisfied
4 = Very important	4 = Very satisfied

$$\text{Relative Problem} = \sqrt{(\text{imp.}) \times (4 - \text{sat.})}$$

higher), but that satisfaction is relatively low on all of these items (scores are 2.5 or lower for 27 of 28 items).

Employment Information

Most of the respondents [41 (78%)] were not working for pay, and all but one of these said they were unemployed because of their disability. Of the nine who were working for pay, four did not have full-time jobs. Six respondents reported that they had been looking for a job for lengths of time ranging from 2 weeks to 4 years (Median: 1.5 months). "Median" means that half had been looking for a job for more than 1.5 months, and half had been looking for less than 1.5 months.

Medical Rehabilitation Facilities

More than a third [12 (38%)] of the respondents had gone to a medical rehabilitation facility or hospital for their disability (see Table 10). Of these, three of every four reported receiving good support from their families during this time. The most common form of support was "emotional" (5 cases). Other forms included:

- Help around my house
- Transportation
- Counseling
- Given rides over and back plus help out at home
- Relocation, obtaining a vehicle
- Financial support

More than half of the respondents [7 (58%)] received follow-up, either through mail, phone call, or home visit, from a:

- Social worker
- IL or VR counselor
- Community health representative
- Their doctor

Table 10

Experience with Medical Rehabilitation Facilities (MRF)

MRF/HOSPITAL QUESTION	Yes (#)	Yes (%)	No (#)	No (%)
Did you go to a rehab medical facility or hospital for your disability?	12	38%	20	62%
Did you get good support from your family during this time? (% based on 12 who answered 'yes')	9	75%	3	25%
Upon discharge, did you later receive a follow-up by mail, phone call, or home visit? (% based on 12)	7	58%		
Upon discharge, was your home made accessible so you could live independently? (% based on 12)	4	33%		
Upon discharge, were you left without any resources for services? (% based on 12)	4	33%		
Upon discharge, a counselor visited with me. (% based on 12)	3	25%		

Two respondents answered the question, "What happened when no family support was received?" and reported:

- Resulted in becoming more dependent on family for activities of daily living (bathing, dressing, eating)
- Was sent to a nursing home or similar facility to receive personal care

Three respondents reported that upon discharge from a medical rehabilitation facility, that it took a counselor five to six months to visit.

Monthly Family Income

Median monthly family income was reported as \$400 - \$599. This income level was reported as "livable" by 11 of 19 respondents. Only two respondents reported less family income, and both of these considered that income not enough to live on. Nine respondents reported at least \$600 of family income per month, and most of them (6, 67%) considered their monthly family income not enough to live on.

Independent Living Services

Only one respondent reported receiving IL services currently. The services were received in Zuni, NM. The Independent Living Rehabilitation Services (ILRS) were reported as very satisfying, and employment placement was received about two months after receiving IL services. One other respondent may have received IL services in the past, indicating that when the case was closed, they had agreed with the counselor that it was time to close the case.

Personal Assistance Services

Respondents were told that "personal assistance" means one human being assists another person with a disability to do something the person with a disability could not do for himself/herself, and that people get assistance with various things, such as getting in or out of bed, dressing, eating, bathing, cooking, shopping, laundry, transportation, or reading. Most of the respondents [23 (72%)] indicated that they had a person who helps them do these things. That person was almost always a member of their immediate family (spouse, mother, sister, son, daughter), usually a female (wife, mother, sister, daughter or grandmother: n=12; son, husband: n=4.) The most common activities that the assistant did for them were transportation (6), cooking (3), cleaning (2), shower/bath (2), leading to places (2), and "everything listed" (2). Ten other activities each received one affirmative

response (feeding, visiting, household chores, daily chores, bowel, emotional support, reading, financial support, caring for, shopping).

Personal life goal(s) that the respondents hoped to meet by using their personal assistant were to: complete daily activities (3), mobility (2), happiness (2), good life (1), normal life (1), easier life (1), exposure to people (1), and assistance (1). Some of the situations that the respondents reported that their personal assistance worked well for them were in daily living, transportation, laundry, understanding their problems, tying string from house to outside bathroom, and getting to appointments on time.

Family members were not the personal assistant only of necessity; most respondents [17 (53%)] preferred a volunteer member of their family or extended family to anyone paid by government money (3). Two respondents actually thought that if their family member assistant was paid by the government, it would be a bad thing ("spoil them"; "take away the essence of the family"). Six thought it could be a good thing, such as that their family member could use the money (3), motivate them (2), they could be better educated in sign (1), but eight thought it wouldn't make any difference. The pattern of these answers suggests that most respondents thought that personal assistance was and should be a family matter.

Qualitative Data from Community Meetings

During the Ramah and Crownpoint community meetings conducted on January 25 and 26, 1996, there appeared to be concern for funding community-based services for consumers, outreach services by service providers, and greater access to rehabilitation services. The comments provided below were transcribed from the community meetings; due to limited space, all the comments made during the meetings cannot be published. Quotes were chosen because they articulated a point of view not elsewhere revealed by research questions, and the quotes provide an unexpected insight into research data. The reader should get a flavor of how the

community meetings went with many concerns about access to services, funding issues, lack of community service providers, and tribal leaders not addressing the needs of tribal members with disabilities.

Funding Issues

Consumer: *And in all of this paperwork, and all these procedures, and all these 800 numbers, and all the forms they have to fill out, we spend an awful lot of dollars when we could reduce the amount that is spent by actually giving to either the community or those that are in need of those dollars.*

Consumer: *The tribes don't have the money to build a ramp. The tribes are always asking, "Well, we need the wood, we need the lumber, we need the nails, (and) we need the manpower to do this." You know what I'm saying, it's like the services are available, but it's always the money that it all boils down to.*

Service Provider: *And I understand the frustrations you all have and maybe that's a beginning step for all of us. In this community, we all get together and we express our frustrations, and we try to identify some funding sources to help you, to help consumers here in the community to maintain and/or increase independent living in the community.*

Consumer: *I always have brought this thing up in my community or elsewhere about handicaps, veterans and those guys. The only time that these people would bring us up is in their election times, even in the state government. They use the handicapped to get funded. When they get funding here on the reservation they don't look at us, they never try to help us out--the elderly people or handicapped people or veteran people. They don't look at those things. When they get their money, they are gone.*

Communication
with Native
Consumers

Consumer: *All the Native Americans, we know what struggle is, and it's up to us to take the initiative and have the drive and do it for ourselves.*

Consumer: *They ask you how much you get for your income and this and that, and I didn't know that all these services they provide--some of them are free and if these people out there that live that are working with them would tell them straight out how to go about it, I think they would understand.*

Consumer: *As the service providers and the people that are being paid to help you, don't be afraid to ask them, because they are the ones who are supposed to help you.*

Consumer: *I think the community--the disabled community should get together and kind of do a talk with service*

providers and (we) tell them what their needs are. And kind of get their phone numbers or try to get (urban) service providers out here to the reservation to help them (American Indian consumers).

Consumer: You have to keep calling them (service providers) and calling them. It takes a long time, you just have to keep calling, and calling, and say, "Hey, I need some help." And finally they'll get someone to you. But it takes a long time. Things that are good take a long time. That's one thing I want to stress.

Service Provider: Okay, when we come out into a community, we always notify maybe the CHR (Community Health Representative) or someone to come out with us. And while (at) the community itself, we try to get their HIP program, the Home Improvement Program. We try to get their (HIP) people out there so we can train them to put the handrails in, how to put different things, (and) how to build a ramp.

Service Provider: Or they'll (a service provider) ask the family for maybe 20% or something. Or even 10%. They'll ask the families for a percentage. The reason for that is, is that if you put your hard-earned money into that ramp there, then you're going to take care of it. But if you get it for free, you know, you're going to let it go to--you're not going to

take care of it but sometimes if you can't really afford it, we try all kind(s) of ways to get money for that ramp for you.

Service Provider: Now what I was saying before that I'd like to emphasize is that Social Security Administration was one of the places people did go to. And I think that's one place where you can go to disseminate information for service providers on some of the services that you offer. And another one is the Indian Health Service, the IHS facilities in this area. People go there for (medical) help. When they go there for (medical) help, why not disseminate information there on the type of services that you provide?

Pow-wow
Accessibility

Consumer: The thing, probably we need to do is when we see a pow-wow advertised in an area, is to give them a call and let them know to make all the facilities acceptable. That is just the bottom line. I don't know if you could do that at a traditional ceremony. I have never seen a port-a-potty at a traditional ceremony.

Consumer: I have been to pow-wows and a couple of activities and I've found the lack of accessible bathrooms for people in wheelchairs and people who have problems using the regular bathrooms the tribal members went to the tribal Pow-Wow Committee and asked for funding for portable bathrooms and they got them.

Communication
with Service
Providers

Service Provider: Sometimes when we are out there as a service provider we end up being not expert in everything but at least being able to know who to refer to. But one thing, when it comes to any kind of medical condition or whatever I usually have the help of the medical profession, to make sure that the devices are what they really need.

Consumer: I live out in the rural area and I haul water round trip--25 miles and the only guys that help me are my kids. I have a boy and a girl and they are only small and we tried to haul water out there and I was just trying to get somebody to get some water out there or even run a line out there or drill a well out there, but they never did. They never had time. I wrote letters to the IHS and I think there are a lot of handicapped people on the reservation that are just really neglected. I don't know why but they could respond or say something, "I can't do it," "I can't help you," that would be good.

Discussion

Until this project was done, there was limited information on the independent living needs of American Indians with disabilities who reside New Mexico. This study, conducted by researchers through the AIRRTC at Northern Arizona University, interviewed 32 American Indians with disabilities in northwest New Mexico from October, 1994 to October, 1995. This sample, even though it is small, may reflect the current needs of American Indians with severe/significant disabilities in New Mexico.

Of the 32 interviews conducted, only one interviewee received independent living services at the time of the research. The lack of independent living services may be attributed to the distance from centers for independent living (CILs) to reservations or villages. The nearest CIL to northwest New Mexico is Albuquerque. One CIL had a satellite office at a Pueblo village and a member of the Pueblo village provided independent living services. Although the CIL in Albuquerque provided all four core services, the main service provided by the liaison was systems advocacy.

The 1990 U. S. Census reported that the average age of American Indians was 26 years, considerably younger than the U. S. median age of 33 years. The New Mexico interviewee's average age was 49 years. This may be attributed to elders being more available than the younger population, or that the elders are more likely to reside on reservations than the younger population. The younger population may have more severe disabling conditions that makes it difficult to live on reservations because of the lack of resources.

Sensory impairments, identified as eye and ear conditions, are disproportionately high among American Indians when compared to all races in the U. S. (O'Connell, 1987). Thus, the high prevalence of sensory impairments among American Indians was supported by the New Mexico consumer results.

The interviewees frequently reported blindness, hearing impairment, and hypertension as disabling conditions. This might be attributed to the average age of the interviewee population of 49 years with an age range of 22-85.

Reviewing Table 4 on assistive aides and devices, both medication and eyeglasses tend to be used sometime during the lifetime of an individual. However, the third, fourth, and fifth items listed (wheelchair or scooter, walking stick, walker) are all mobility assistive devices. Interestingly, 80% of the respondents using a wheelchair or scooter indicated that they "needed improvement" to their

wheelchair or scooter. The "needed improvement" for wheelchair or scooter may be attributed to the unpaved roads and sidewalks on reservations or rural areas and lack of resources to maintain disability aides and devices. This indicates that the service providers who are responsible for identifying and/or purchasing these devices and aids need to provide follow-up services. Following up on assistive devices purchased will alleviate the "needs improvement" problem and increase consumer satisfaction.

The New Mexico respondents reported a lack of knowledge about services as one of the most common barriers to receiving needed services. Some of these services were help with services coordination, help with food, dental care, help with clothing, help with housing, job help, medical care, eye/vision care, help with benefits, special transportation, how to cook, clean, or shop, counseling, and help with alcohol abuse.

The most common location of services currently received was the Social Security Administration in Gallup, which may be attributed to the respondents' average age of 49 years. The independent living movement may discourage the medical model; however, in Indian communities, assistance with aids and devices and rehabilitation is needed. The Indian Health Service is frequently utilized for services that are located in various parts of the reservations. The rehabilitation services offered through the CILs and ILPs could consider using the Indian Health Agencies for referrals and providing services. The Indian Health Service is encountering budget cuts; therefore, the CILs and ILPs could consider contracting with the Indian Health Service for IL services that are culturally relevant.

Only one respondent in Zuni received services from an independent living center, two respondents in Zuni received state vocational rehabilitation services, and three respondents received tribal vocational rehabilitation services in Zuni. In Table 5, the most frequently reported activity limitations due to disability were

working on a job, taking care of things/responsibilities, driving, performing manual tasks, self-care at home, writing, walking, and lifting. The need for services from CILs, state, and tribal vocational rehabilitation is supported by "activity limitations due to disability" reported in Table 5.

One of the important findings was that social services are the least used service by the respondents. The most often reported "services needed in past year but not received" were help with services coordination, help with food, dental care, help with clothing, help with housing, and job help. Most of the respondents didn't know of the services or the services were not offered to them. Eleven respondents reported that "hours were not convenient" for them to use services providing help with food [4 (13%)], help with clothing [3 (9%)], and eye/vision care [4 (13%)]. It appears that since food and clothing are basic necessities, extension of business hours could be considered.

The top five consumer concerns identified by the respondents using the problem index, are that:

1. Portable accessible bathrooms are made available at pow-wows and other native social/traditional gatherings.
2. Assistive devices (such as wheelchairs, braces, hearing aids, etc.) are available and affordable.
3. Tribal government and public services respond to the needs of American Indians with disabilities.
4. Public transportation to shopping, medical, and recreation centers is available to people with disabilities.
5. The Indian community understands the needs of its members with disabilities.

The concerns that portable accessible bathrooms be made available at pow-wows and other native social/traditional gatherings reflects the desire of the consumers to participate in Indian gatherings. This desire is not usually considered at most functions, therefore tribal governments need to be educated on this issue so that a tribal policy could be developed for event organizers to consider availability of portable accessible bathrooms. The top four consumer concerns in importance were that:

1. Social service providers should involve family members and extended family members in their rehabilitation.
2. You should feel safe in your home and neighborhood.
3. The Indian community understands the needs of its members with disabilities.
4. Information about legal rights and self-advocacy is available to American Indians with disabilities.

The respondents were least satisfied with "the Indian community understands the needs of its members with disabilities." This perception from the American Indian people with disabilities reflects that able-bodied people in Indian communities are not addressing their needs. On the other hand, respondents indicated that they were most satisfied with "you can call for and get help in an emergency," "your family members understand your disability and how to help you function more effectively," "affordable housing," and "counselor's work." There are some interpretations that can be explored for the top satisfied concern, which is "you can call for and get help in an emergency." For instance, "calling for" could involve yelling for help or using the telephone to call neighbors, family members, or calling the emergency number 911. Whatever arrangements are made, the consumers are satisfied with it.

Of the 32 responses regarding personal assistance services, 23 (72%) of the respondents indicated that they have a person that helps them do things. Almost all of these respondents indicated that their family members [22 (96%)] were helping them with their daily living. This may be attributed to a lack of personal assistance services, or that the native consumers are more inclined to rely on family members, which may be their only option financially. On another hand, this is culturally appropriate since native families are taught to assist family members who are in need financially or with chores such as wood cutting, cooking, and even personal assistance services. This is more likely the case if the consumer resides on the reservation near extended family members' residences. The questionnaires for personal assistance reported a preference for family or extended family members volunteering their time to provide personal assistance.

Due to the rural distances on reservations, transportation was identified as the top activity provided by family members. Other activities included cooking, showering/bathing, leading to places, everything listed (in or out of bed, dressing, eating, bathing, cooking, shopping, laundry, transportation, or reading), and cleaning.

More respondents discussed a personal assistance situation in positive terms than negatively. Some examples of how personal assistance worked for the respondents included daily living, transportation, laundry, understands my problems, tied string from house to outside bathroom, and gets me to appointments on time.

A majority of the respondents indicated that it would be appropriate if their personal assistant could "speak the language." Speaking the native language ensures quality verbal and non-verbal communication, which could enhance personal assistance services.

Conclusions

Several important findings of this study will need to be addressed to improve the quality of life for American Indians with disabilities in northwestern New Mexico. In this study, issues and needs identified by the 32 American Indians with disabilities through personal interviews by a Navajo AIRRTC research technician, Tonilisa Nezz, tell the story of lack of resources for consumers, lack of outreach services to consumers, and lack of knowledge of rehabilitation services by the consumers. Many of the respondents reported more than one disability. The respondents frequently reported sensory and heart conditions as their disabling conditions. The respondents also showed a preference for a volunteer family member or extended family member to be their personal assistant.

Vocational rehabilitation counselors and Centers for Independent Living counselors need to provide employment assistance such as locating a job or providing incentives to employers to hire American Indians with disabilities. Additionally, if independent living counselors are not providing employment-related services, referrals to the appropriate tribal/state vocational rehabilitation agencies need to be made. Over half [22 (69%)] of the respondents reported that their disability limited their "working on a job." Only nine of the respondents reported working for pay, and of those, four were working less than full-time jobs. An average of 1.5 months was reported by six respondents as looking for a job.

Limitations of this study are identified as: (a) the sample of this study was small, (b) it summarized issues from only three counties (Cibola, McKinley, San Juan), (c) the majority of the respondents was from the Navajo tribe, and (d) travel stipends should have been made available to American Indian with disabilities to attend meetings such as working group and community meetings.

The majority of the respondents indicated that they did not know services were available such as: help with services coordination, help with food, dental care,

help with clothing, help with housing, job help, medical care, eye/vision care, how to cook, clean or shop, counseling, and help with alcohol abuse. Transportation for services also affected the respondents ability to get to services, such as "help with service coordination," "help with food," and "help with clothing." Most of these issues are related to basic needs that needs to be addressed for the survival and long term health of the American Indians with disabilities.

Increased public relations and advertisement of services need to occur. The respondents (see Table 7) revealed that the following were *not* common locations of services received: tribal vocational rehabilitation, state division of vocational rehabilitation, veterans affairs administration, independent living centers, and state division of social services.

During the community meetings on discussing the preliminary results of this study in Ramah and Crownpoint, service providers pointed out that the issues uncovered were not new to them and that funding for community-based programs was needed, as well as accessing resources to meet the needs of American Indians with disabilities. While the service providers present heard the interpretation of the preliminary results of this study, very few administrators or policy makers were present. Although the meetings were conducted on the Navajo reservation, no tribal community leaders from the local chapter house were present. Many attendees of the community meetings told the research team that this type of meeting is needed more often, to talk about issues as a group and to bring together service providers and American Indians with disabilities. Apparently, a community meeting primarily focusing on American Indians with disabilities needs and issues had not been done before.

The findings in this study reveal no new issues or conclusions. The challenge continues to be how to find and/or create solutions for meeting the needs of the American Indians with disabilities in New Mexico. Given that policy makers,

tribal and state leaders were not present at the community meetings to listen to the report and hear first hand from the American Indians with disabilities, their family, and the "troops" that work directly with the American Indians with disabilities, a report that documents the issues and concerns cannot be ignored. The research team encouraged the community meeting attendees to use this document to explore tribal, private, state, and federal grants that could meet the needs of the American Indians with disabilities.

Recommendations

These results form the basis for a series of recommendations:

1. Arrangements made by centers for independent living in urban areas should emphasize the outreach aspects of providing independent living services to American Indians with disabilities by providing more financial resources for outreach services to American Indian communities, and spending more time getting to know the community.
2. The New Mexico Statewide Independent Living Committee (SILC) should identify a minimum of six target communities and Pueblo villages in rural and reservation areas. The SILC should hold at least one meeting per year in each of these communities, and should provide mentoring, training seminars, and technical assistance to consumer groups in these communities.
3. The centers for independent living, the New Mexico Division of Vocational Rehabilitation, and the Navajo Nation Office of Special Education and Rehabilitative Services need to collaborate on providing services to American Indian consumers, including counseling, how to cook, clean or shop, special transportation, help with benefits, job help, help with housing, and service help. Some examples of getting information to grass-roots consumers on the reservation could be the local radio station, tribal newspapers, culturally

relevant posters, or setting up booths at fairs, tribal events, or rodeos.

4. The New Mexico Technology Access Program should teach American Indian consumers in northwestern New Mexico how to promote systemic change through new legislation, policies, and practices.
5. Since the majority of the respondents did not know about many of the services that were available, the state SILC plan should include dissemination of information about independent living services, designed for American Indian consumers, to Indian Health Service and Social Security Administration offices in American Indian communities.
6. Independent living counselors and SILC members need to be aware that members of different tribal cultures, even if they reside in the same county, may have different basic needs. In other words, Navajo, Zuni, and Laguna consumers may have different needs, and addressing those needs should be culturally relevant.

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Appendix A

Research Technician's Job Description

AMERICAN INDIAN REHABILITATION RESEARCH AND TRAINING CENTER
Institute for Human Development
Arizona University Affiliated Program
Northern Arizona University

Job Description

Title

Research Technician (On-site Research Coordinator for AIRRTC Project R-40)
VR Independent Living Counselor Effects on Independent Living Outcomes for American Indians with Disabilities

Prime Function

Under the supervision of Dr. Robert Schacht, performs work of considerable difficulty in directing or performing a wide variety of standard and specialized tasks on a research project.

Duties and Responsibilities

A. Planning

- ❖ Meets with working group and project staff to develop questionnaire
- ❖ Plans community meeting at end of project for all participants

B. Interviewing

- ❖ Meets with project staff to review interviewing procedures
- ❖ Recruits 35 American Indians with severe disabilities to interview
- ❖ Explains the purpose of the interview and makes appointments for interviews with American Indians/Alaska Natives with severe disabilities within the assigned time frame
- ❖ Obtains signature on Informed Consent Form of person to interviewed
- ❖ Travels to homes of consumers or other mutually agreeable sites to conduct interviews
- ❖ Completes all paperwork relating to interviews, such as invoices for payment, excess travel expenses, and contact log which includes a record of all contacts, record of interviews completed, and mileage, etc.
- ❖ Completes all assigned interviews within the assigned time frame
- ❖ Returns all questionnaires and paperwork to project staff in a timely and appropriate manner

C. Other tasks

- ❖ Maintains close communication with project staff
- ❖ Informs supervisor immediately of any problems related to the project

Knowledge and Skills

- ❖ Skill in effective interpersonal relations
- ❖ Skill in written and verbal communication, especially knowledge of values and communication styles of the various American Indian tribes represented in New Mexico.

Minimum Qualifications

- ❖ Bachelor's degree in area related to field of work **OR** four years related experience
- ❖ Knowledge and/or experience in working with American Indians/ Alaska Natives with disabilities is preferred
- ❖ Ability to perform all duties and responsibilities in a timely and appropriate manner
- ❖ Reliable transportation and ability to travel in the state

Compensation

Subdivided as follows:

Advance training, planning, and recruiting, approximately 40 hours @ \$9 - \$10.50 per hour	\$ 400
Interviews, 35 @ \$30 each	\$1,050
Planning community meeting, approximately 30 hours @ \$9 -10.50 per hour	\$ 300
Total salary	<hr/> \$1,750

For more information, contact:

Priscilla Lansing Sanderson
Robert M. Schacht
AIRRTC
PO Box 5630
Flagstaff, AZ 86011-5630
(602)523-4791

Appendix B

Interview Instrument

INDEPENDENT LIVING CONCERNS OF
AMERICAN INDIANS WITH DISABILITIES
NEEDS ASSESSMENT

CONSUMER PILOT INTERVIEW

New Mexico

March 6, 1995

AMERICAN INDIAN REHABILITATION
RESEARCH AND TRAINING CENTER



Institute for Human Development
Arizona University Affiliated Program

PO Box 5630

Flagstaff, AZ 86011-5630

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INDEPENDENT LIVING CONCERNS OF AMERICAN INDIANS WITH DISABILITIES NEEDS ASSESSMENT

CONSUMER PILOT INTERVIEW

Priscilla Lansing Sanderson, M.S., C.R.C.

and

Robert M. Schacht, Ph.D.

Project Directors

On-Site Research Coordinator

AMERICAN INDIAN REHABILITATION
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Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services,
U. S. Department of Education.*

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CONSUMER IDENTIFICATION PAGE

(To be used for interview verification only)

Name of Interviewee _____ ID Number _____
[for Office Use Only]

Street/P.O. Box _____

City _____ State _____ Zip _____

Telephone _____ (Home) _____ (Work) _____
_____ (TTY-TDD) _____ (Message) _____

Best time to call: _____

Interview verification

☐ Interviewee contacted (Date: _____)

☐ Unable to contact Interviewee
Reason: _____

Certified by: _____ Date: _____

[To be completed by Supervisor]

CONSUMER INTERVIEW

[Be sure to obtain signature on INFORMED CONSENT FORM prior to beginning.]

INTERVIEW INFORMATION

II-1. Location of Interview
 (1) ☐ Interviewee's home
 (2) ☐ Other *[please specify]*: _____

II-2. Was interview conducted in a Native language?
 (1) ☐ Yes (2) ☐ No (3) ☐ Partially

II-2a. *[If yes]* What language? _____

II-2b. *[If yes]* Was interpreter used? (1) ☐ Yes (2) ☐ No

II-2c. *[If yes]* Interpreter's Name _____

II-3. Date of Interview _____

II-4. Time spent _____ Begin _____ End _____ *[minutes]*

II-5. What is the relationship of the interviewee to the person with a disability?
 (1) ☐ Person with disability (i.e., Self)
 (2) ☐ Parent
 (3) ☐ Grandparent
 (4) ☐ Spouse
 (5) ☐ Son/Daughter
 (6) ☐ Other _____

GENERAL INFORMATION

(This information refers to person with disability)

GI-1. ID Number _____
[For Office Use Only]

GI-2. City (Residence) _____

GI-3. County _____

GI-4. Home Reservation _____

GI-5. State *[if other than New Mexico]* _____

GI-6. Zip Code _____

GI-7. Home Phone (1) ☐ Yes (2) ☐ No

Age _____

GI-9. [Sex] (1) ☐ Male (2) ☐ Female

GI-10. Tribal (Nation) Affiliation(s) _____

GI-11. Marital Status [If "single", ask if "never married"]

- (1) ☐ Never married
 (2) ☐ Married [official or common law]
 (3) ☐ Divorced
 (4) ☐ Widow(er)
 (5) ☐ Committed same sex relationship
 (6) ☐ Other _____

GI-12. Do you have a Tribal I.D., roll number or membership card?

- (1) ☐ Yes (2) ☐ No

GI-13. Do you have a CDIB (certificate of degree of Indian blood) card?

- (1) ☐ Yes (2) ☐ No

GI-14. Are you a registered voter in your tribe?

- (1) ☐ Yes (2) ☐ No

GI-15. How much income does your family household receive each month? [include all sources] \$ _____

- | | | | | | | | |
|--------|---|------|------------------------------|--------|---------|-------------------------------|-------------------------------|
| \$ 0 | - | 199 | <input type="checkbox"/> (1) | \$1200 | - | 1399 | <input type="checkbox"/> (7) |
| \$200 | - | 399 | <input type="checkbox"/> (2) | \$1400 | - | 1599 | <input type="checkbox"/> (8) |
| \$400 | - | 599 | <input type="checkbox"/> (3) | \$1600 | - | 1799 | <input type="checkbox"/> (9) |
| \$600 | - | 799 | <input type="checkbox"/> (4) | \$1800 | - | 1999 | <input type="checkbox"/> (10) |
| \$800 | - | 999 | <input type="checkbox"/> (5) | \$2000 | or more | <input type="checkbox"/> (11) | |
| \$1000 | - | 1199 | <input type="checkbox"/> (6) | | | | |

GI-16. Is your income enough to live on? (1) ☐ Yes (2) ☐ No
 [If no] Please explain _____

GI-17. Why do you live in your present city or community? [For example, did you move here because of services? To find a job? To go to school? Born and raised here?] _____

GI-18. How many years have you lived in this city or community?

- (1) ☐ Less than one year (2) _____ Years

GI-19. Do you have another home? If yes, where?

- (1) ☐ Yes (2) ☐ No
 (name of city or community) _____

GI-20. Where would you prefer to live?

- (1) ☐ Present city or community
 (2) ☐ Another place [specify] _____

GI-21. Do you have a reservation or Tribal land or allotment area that you consider home? (1) ☐ Yes (2) ☐ No

GI-21a. Where is that? _____

GI-21b. [If yes] How frequently do you visit your home reservation or Tribal land?

- (1) ☐ Once a week
 (2) ☐ Once a month
 (3) ☐ Six times a year or so
 (4) ☐ Two or three times a year
 (5) ☐ Once a year
 (6) ☐ Never
 (7) ☐ Other [specify] _____

GI-21c. Would you live on a reservation or Tribal land if the services you needed were there?

- (1) ☐ Yes (2) ☐ No

GENERAL INFORMATION (continued)

22. What language is spoken most in your home?

- (1) ☐ Tribal language
 (2) ☐ English
 (3) ☐ Combination of Tribal language and English
 (4) ☐ Other(s) _____

GI-23. What language would you prefer human service workers (such as independent living or rehabilitation counselors, food stamps workers, health care workers) to use when helping you?

- (1) ☐ Tribal language
 (2) ☐ English
 (3) ☐ Combination of Tribal language and English
 (4) ☐ Sign language for the deaf (type: _____)
 (5) ☐ Other _____
 (6) ☐ Not Important

GI-24. [Get card] What means of transportation do you use the most?

[Show card, select only one] (1) ☐ Yes (2) ☐ No

- (1) ☐ Bicycle
 (2) ☐ Friend's/family member's car
 (3) ☐ Bus
 (4) ☐ Taxi
 (5) ☐ Van from Indian Organization
 (6) ☐ Walking
 (7) ☐ Hitchhiking
 (8) ☐ Personal car or truck
 (9) ☐ Other [Specify] _____

DISABILITY INFORMATION

Please describe your condition, long-term illness, handicap(s), disability or disabilities [check all that apply]

- | | |
|--|--|
| (1) <input type="checkbox"/> Amputation | (19) <input type="checkbox"/> Mental Retardation |
| (2) <input type="checkbox"/> Anxiety | (20) <input type="checkbox"/> Multiple Sclerosis ("MS") |
| (3) <input type="checkbox"/> Arthritis | (21) <input type="checkbox"/> Muscular Disease (such as, Muscular Dystrophy) |
| (4) <input type="checkbox"/> Bipolar Disorder | (22) <input type="checkbox"/> Neurological Impairment |
| (5) <input type="checkbox"/> Blindness | (23) <input type="checkbox"/> Orthopedic Disorder |
| (6) <input type="checkbox"/> Cancer | (24) <input type="checkbox"/> Personality Disorder |
| (7) <input type="checkbox"/> Cerebral Palsy | (25) <input type="checkbox"/> Polio |
| (8) <input type="checkbox"/> Chronic Depression | (26) <input type="checkbox"/> Schizophrenia |
| (9) <input type="checkbox"/> Deaf | (27) <input type="checkbox"/> Scoliosis (curved spine) |
| (10) <input type="checkbox"/> Diabetes | (28) <input type="checkbox"/> Specific Learning Disability |
| (11) <input type="checkbox"/> Eating Disorder | (29) <input type="checkbox"/> Spinal Cord Disorders |
| (12) <input type="checkbox"/> Epilepsy | (30) <input type="checkbox"/> Stroke |
| (13) <input type="checkbox"/> Hearing Impairment | (31) <input type="checkbox"/> Substance abuse [including alcohol, street drugs, glue, or whatever] |
| (14) <input type="checkbox"/> Heart Problems | (32) <input type="checkbox"/> Tuberculosis ("TB") |
| (15) <input type="checkbox"/> Hypertension (High Blood Pressure) | (33) <input type="checkbox"/> Traumatic brain injury |
| (16) <input type="checkbox"/> Kidney Disorder | (34) <input type="checkbox"/> Visual Impairment |
| (17) <input type="checkbox"/> Low Vision | (35) <input type="checkbox"/> Other _____ |
| (18) <input type="checkbox"/> Lung Disorder | |



DISABILITY INFORMATION (continued)

- DI-2. [Get Card] Do you use any of the following because of your disability?
[Show Card] [If not used currently, ask "Do you need?" If used currently ask, "Do you need new or improved," For example, glasses]

	Used currently	[If not used] Need	[If used] Need Improvement
(1) Walking stick or Cane	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(2) Crutch(es)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(3) Wheelchair or scooter [type] <input type="checkbox"/> Manual <input type="checkbox"/> electric <input type="checkbox"/> scooter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(4) Modified vehicle or van	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(5) Eye-Glasses/Contact Lenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(6) Magnifying Lens or Telescope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(7) Braille	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(8) Long (white) cane	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(9) Sign Language [type]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(10) Lip Reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(11) Walker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(12) Hearing Aid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(13) Prosthesis/Brace	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(14) Medications (such as insulin)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(15) Indian Medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(16) Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- DI-3. [If using medication or Indian Medicine] What kind of medication(s) do you use and for what reason(s)?

- DI-4. Is your disability a result of:

- (a) military service (1) ☐ Yes (2) ☐ No
(b) automobile accident (1) ☐ Yes (2) ☐ No
(c) an infectious disease (1) ☐ Yes (2) ☐ No
(d) other[specify] _____

- DI-5. Is there anything more you'd like to tell me about your **most important** disability? [For example, Which disability bothers you most? Write word-for-word how primary disability is described]

- DI-6. Have you had this disability since birth?

- (1) ☐ Yes (2) ☐ No

DI-6a. [If no] In what year did this disability begin? _____

DI-6b. [If no] How old were you when this disability began? _____



DISABILITY INFORMATION (continued)

DI-8. [Get Card] Does your disability (ies) limit you in doing the following activities?
[Show Card; one by one, read *through* list with interviewee, marking each response.]

	Yes or Sometimes	No
(1) Reading	1	2
(2) Writing	1	2
(3) Seeing	1	2
(4) Hearing	1	2
(5) Speaking	1	2
(6) Remembering	1	2
(7) Use of arms	1	2
(8) Use of hands	1	2
(9) Walking	1	2
(10) Standing	1	2
(11) Sitting	1	2
(12) Sleeping	1	2
(13) Lifting	1	2
(14) Breathing	1	2
(15) Learning	1	2
(16) Driving	1	2
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	Yes or sometimes	No
(17) Performing manual tasks	1	2
(18) Using public transportation	1	2
(19) Working on a job (such as working full-time not missing work)	1	2
(20) Ability to work in places with access to controlled substances (such as alcohol or drugs)	1	2
(21) Taking care of yourself at home (dressing, bathing, toileting, eating, getting in/out of bed, and so on.)	1	2
(22) Taking care of things (such as household chores, doing paperwork, going shopping, getting around in your community)	1	2
(23) Getting along with people	1	2
(24) Anything else? _____	1	2
77		



SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS)

I'm going to ask you some questions about the services that you have received within the past year from an agency. how helpful the services were, and why you may not have received some of the services you need or want [SI-1 to SI-15 refer to within the past year, circle all that apply]

	Column A		Column B					Column C		Column D							
	Have you RECEIVED help/services?		How HELPFUL was the service? [Show Card]					Did you NEED or WANT the service?		What were the BARRIERS stopping you from getting the service? [Show card; circle all that apply]							
	Yes	No						Yes	No								
<i>[Get cards]</i>																	
Within the Past Year																	
SI-1. Has anyone helped you with services or put you in touch with those who could help you?	†	††						†††									
	1	2	1	2	3	4	5	1	2	1	2	3	4	5	6	7	8
SI-2. Have you received help getting																	
a. food	1	2	1	2	3	4	5	1	2	1	2	3	4	5	6	7	8
b. clothing	1	2	1	2	3	4	5	1	2	1	2	3	4	5	6	7	8
c. housing	1	2	1	2	3	4	5	1	2	1	2	3	4	5	6	7	8
78	† 1-Yes [go to Col B] †† 2-No [go to Col C]		[Show Card] 1-Made my problems much worse 2-Not helpful 3-OK, so-so 4-Helpful 5-Made my problems much better					††† 1-Yes [go to Col D]		[Show Card] 1-Did not know of service. 2-The services were not offered to me 3-I had no way of getting to the service 4-The hours were not convenient 5-I could not afford to use the service 6-I wasn't feeling well enough to use the service 7-Agency personnel were not sensitive to my needs 8-Other (please explain)							
																	79



SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS) (continued)

Column A		Column B	Column C		Column D
Have you RECEIVED help/services?		How HELPFUL was the service?	Did you NEED or WANT the service?		What were the BARRIERS stopping you from getting the service? [Circle all that apply]
Yes	No		Yes	No	
Within the Past Year					
SI-6 Have you received help to get or keep a job, or training (including education) to be able to work?	†		†††		
	1	1 2 3 4 5	1	2	1 2 3 4 5 6 7 8
SI-7. Have you received medical care?	1	1 2 3 4 5	1	2	1 2 3 4 5 6 7 8
SI-8. Have you received dental care?	1	1 2 3 4 5	1	2	1 2 3 4 5 6 7 8
SI-9. Have you received eye or vision care?	1	1 2 3 4 5	1	2	1 2 3 4 5 6 7 8
† 1-Yes [go to Col B] †† 2-No [go to Col C]		[Show Card] 1-Made my problems much worse 2-Not helpful 3-OK, so-so 4-Helpful 5-Made my problems much better	††† 1-Yes [go to Col D]		[Show Card] 1-Did not know of service. 2-The services were not offered to me 3-I had no way of getting to the service 4-The hours were not convenient 5-I could not afford to use the service 6-I wasn't feeling well enough to use the service 7-Service provider was not helpful 8-Other (please explain)

SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS) (continued)

Column A		Column B	Column C		Column D
Have you RECEIVED help/services?		How HELPFUL was the service?	Did you NEED or WANT the service?		What were the BARRIERS stopping you from getting the service? [Circle all that apply]
Yes	No		Yes	No	
Within the Past Year					
SI-10. Have you received counseling, such as peer, individual, group, or family counseling?	†	††	†††		
1	2	1 2 3 4 5	1	2	1 2 3 4 5 6 7 8
SI-11. If you have had problems with alcohol, have you had help to handle any of these problems?	1	2	1	2	1 2 3 4 5 6 7 8
SI-12. If you have had problems with drugs, have you had help to handle any of these problems?	1	2	1	2	1 2 3 4 5 6 7 8
SI-13. If you have had problems with tobacco, have you had help to stop using it?	1	2	1	2	1 2 3 4 5 6 7 8
† 1-Yes [go to Col B] †† 2-No [go to Col C]		[Show Card] 1-Made my problems much worse 2-Not helpful 3-OK, so-so 4-Helpful 5-Made my problems much better	††† 1-Yes [go to Col D]		[Show Card] 1-Did not know of service. 2-The services were not offered to me 3-I had no way of getting to the service 4-The hours were not convenient 5-I could not afford to use the service 6-I wasn't feeling well enough to use the service 7-Agency personnel were not sensitive to my needs 8-Other (please explain)

SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS) (continued)

Column A		Column B	Column C		Column D
Have you RECEIVED help/services?		How HELPFUL was the service?	Did you NEED or WANT the service?		What were the BARRIERS stopping you from getting the service? [Circle all that apply]
Yes	No		Yes	No	
Within the Past Year					
†	††		†††		
1	2	1 2 3 4 5	1	2	1 2 3 4 5 6 7 8
(Women Only)					
SI-15. Have you had					
1	2	1 2 3 4 5	1	2	1 2 3 4 5 6 7 8
a. a low birthweight baby					
1	2	1 2 3 4 5	1	2	1 2 3 4 5 6 7 8
b. prenatal care					
† 1-Yes [go to Col B] †† 2-No [go to Col C]		[Show Card] 1-Made my problems much worse 2-Not helpful 3-OK, so-so 4-Helpful 5-Made my problems much better	††† 1-Yes [go to Col D]		[Show Card] 1-Did not know of service. 2-The services were not offered to me 3-I had no way of getting to the service 4-The hours were not convenient 5-I could not afford to use the service 6-I wasn't feeling well enough to use the service 7-Agency personnel were not sensitive to my needs 8-Other (please explain)



SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS) (continued)

SI-16. Now I'm going to ask you some questions about services you are receiving currently: Are you currently receiving help or assistance for your disability(ies) from any of the following persons or programs? [Show Card; one by one, read through list with interviewee, marking each response]

		[If Yes] Where?		
		Yes	No	State
(1)	Private Medical Doctor	1	2	
(2)	Psychologist	1	2	
(3)	Eye Doctor (optometrist, ophthalmologist)	1	2	
(4)	School (such as teacher, principal, counselor)	1	2	
(5)	State Division of VR [Vocational Rehabilitation]	1	2	
(6)	State Division of VR-Independent Living Rehabilitation Services	1	2	
(7)	Independent Living Center [specify] _____	1	2	
(8)	Tribal VR [Vocational Rehabilitation]	1	2	
(9)	State Division of DD [Developmental Disabilities]	1	2	
(10)	State Division of Social Services [specify] _____	1	2	
(11)	County or City Health Clinic [specify] _____	1	2	
(12)	Mental Health Program [specify] _____	1	2	
(13)	Social Security Administration (SSI, SSDI)	1	2	
(14)	Alcohol/substance abuse Counseling Program [specify] _____	1	2	
(15)	State Job Service Program (such as JTPA)	1	2	
(16)	Indian Health Agency [specify] _____	1	2	
(17)	Senior Citizens Program [specify] _____	1	2	
(18)	Veterans Affairs Administration	1	2	
(19)	Medicare/Medicaid	1	2	
(20)	Other Indian Service Agency [specify] _____	1	2	

(Question continued on next page)

**SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS) (continued)**

SI-16. (Continued from previous page) Now I'm going to ask you some questions about services you are receiving currently: Are you currently receiving help or assistance for your disability(ies) from any of the following persons or programs? [Show Card; one by one, read through list with interviewee, marking each response]

		[If Yes] Where?			
		Yes	No	City	State
(21)	Sweat Lodge	1	2		
(22)	Indian Medicine	1	2		
(23)	Your Church	1	2		
(24)	Indian Center [specify] _____	1	2		
(25)	Community Health Reps	1	2		
(26)	Public Health Nurse	1	2		
(27)	Medical Rehab Facility/Center [specify] _____	1	2		
(28)	Other [specify] _____	1	2		

SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS) (continued)SI-17. *[If yes to Independent Living Center on page 12]*Were there any barriers that made it difficult to complete IL services? (1) ☐ Yes (2) ☐ NoSI-17a. *[If yes]* please check reasons

- (1) ☐ Lack of transportation/unreliable transportation
- (2) ☐ Language differences
- (3) ☐ Didn't understand what type of services was available to me
- (4) ☐ No home phone
- (5) ☐ ILC did not have adequate funding to cover my services
- (6) ☐ Didn't know the status of my case. The counselor rarely kept in touch with me.
- (7) ☐ My Indian culture and values *Explain:* _____

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SI-18. As the result of receiving IL services, did it encourage you to seek or request for employment placement? (1) ☐ Yes (2) ☐ NoSI-18a. *[If yes]* How soon after receiving IL services

- (1) ☐ 1 month or less
- (2) ☐ 2 months
- (3) ☐ 3 months
- (4) ☐ 4 months
- (5) ☐ 5 months
- (6) ☐ 6 months or more

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SI-19. *[Get card]* Which resource from the following list *[Show Card]* has given you the most useful information about services that can help you with your disability? *[Mark no more than three responses]*

- (1) ☐ Newspaper *[which one?]* _____
- (2) ☐ Magazines
- (3) ☐ Books
- (4) ☐ Pamphlets, brochures & newsletters
- (5) ☐ Radio *[station?]* _____
- (6) ☐ TV *[channel?]* _____
- (7) ☐ Friend
- (8) ☐ Relative
- (9) ☐ School
- (10) ☐ Tribal Council Member
- (11) ☐ Independent Living Center
- (12) ☐ VR Counselor
- (13) ☐ IL Counselor
- (14) ☐ VR /IL Rehab Services
- (15) ☐ Community Health Reps
- (16) ☐ Medical Rehab Social Worker
- (17) ☐ Indian Health Agency *[specify]* _____
- (18) ☐ Indian Service Agency *[specify]* _____
- (19) ☐ Indian Center *[specify]* _____
- (20) ☐ Religious Worker or Church Worker
- (21) ☐ Other *[specify]* _____

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SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS) (continued)

- SI-20. Have you received IL services or worked with an ILR counselor? SI-27. Would you say that your IL or Rehabilitation Counselor has been
(1) ☐ Yes (2) ☐ No *If no, please skip to SI-37.]* (1) ☐ very helpful?
(2) ☐ Sometimes helpful?
(3) ☐ Not helpful?
- SI-21. Overall, how satisfied are you with the services that you received from your Independent Living Rehabilitation counselor?
(1) ☐ Very satisfied (2) ☐ Satisfied
(3) ☐ Dissatisfied (4) ☐ Very dissatisfied
(5) ☐ Did not have an ILR counselor
- SI-22. Did the people with ILRS schedule appointments that were soon enough?
(1) ☐ Most of the time
(2) ☐ Some of the time
(3) ☐ Not much of the time
- SI-23. Did they return your phone calls?
(1) ☐ Most of the time
(2) ☐ Some of the time
(3) ☐ Not much of the time
- SI-24. Were you treated with courtesy and respect by the office staff?
(1) ☐ Most of the time
(2) ☐ Some of the time
(3) ☐ Not much of the time
- SI-25. Do you feel your Rehabilitation Counselor listened to your needs?
(1) ☐ Most of the time
(2) ☐ Some of the time
(3) ☐ Not much of the time
- SI-26. Did you select the goal(s) you wanted to reach with the help of ILRS?
(1) ☐ Yes
(2) ☐ Somewhat
(3) ☐ No
- SI-27a. Comments about rating: _____

- SI-28. How well did you get along with your IL or Rehabilitation Counselor?
(1) ☐ great
(2) ☐ OK
(3) ☐ not very much
- SI-29. Do you feel that your Rehabilitation Counselor
(1) ☐ should have assisted you more?
(2) ☐ assisted you about as much as should be expected?
(3) ☐ should have assisted you less?
- SI-30. When decisions were made about your independent living services, do you feel that
(1) ☐ they were your decisions?
(2) ☐ other people made decisions and didn't include you?
(3) ☐ you were sometimes included, but not as much as you would like?
- SI-31. When your case was being closed, did you agree that it was time to stop working with your Rehabilitation Counselor, at least for the time being?
(1) ☐ Yes (2) ☐ No (3) ☐ NA



SERVICES INFORMATION (FORMAL SUPPORT SYSTEMS) (continued)

SI-32. Did your IL Counselor give you a brochure about IL services?
(1) ☐ Yes (2) ☐ No (3) ☐ Don't know

SI-33. Did your IL Counselor explain the steps in the IL process and how long they may take?
(1) ☐ Yes (2) ☐ No (3) ☐ Don't know

SI-34. Did your IL Counselor ask you if these steps were OK with you?
(1) ☐ Yes (2) ☐ No (3) ☐ Don't know

SI-35. Did your IL Counselor explain your right of appeal?
(1) ☐ Yes (2) ☐ No (3) ☐ Don't know

SI-36. How satisfied are you with your ILRS services?
(1) ☐ Very satisfied (2) ☐ Satisfied
(3) ☐ Dissatisfied (4) ☐ Very dissatisfied

SI-37. Are there any services you need that you are not receiving?
(1) ☐ Yes (2) ☐ No

SI-38. [If yes] Please describe these services.

CONSUMER CONCERNS

[Get Cards] I am going to read to you several statements. Please tell me how important each statement is to you [show "Importance" card] and how satisfied you are that each statement is true [show "Satisfaction" card]. Please answer from your own personal experience or, if you have no personal experience on this subject, from what you know about other American Indians who have disabilities in your community.

[Use the following numerical rating system for the importance and satisfaction columns; read through key with interviewee.]

Importance	Satisfaction
0 = Of no concern to me	0 = Very dissatisfied
1 = Not important	1 = Dissatisfied
2 = Somewhat important	2 = Somewhat satisfied
3 = Important	3 = Satisfied
4 = Very important	4 = Very satisfied

	How important is it to you that . .. [Show card]	How satisfied are you that ... [this is true; that this happens in your community] [Show card]
	not very	not very
Community and Family		
CC-1. ...the Indian community understands the needs of its members with disabilities.	0 1 2 3 4	0 1 2 3 4
CC-2. ...your family members understand your disability and how to help you function more effectively.	0 1 2 3 4	0 1 2 3 4
CC-3. ...portable accessible bathrooms are made available at pow-wows and other native social/traditional gatherings.	0 1 2 3 4	0 1 2 3 4
CC-4. ...local TV, radio, & newspapers provide education and adequate information for American Indians who have disabilities.	0 1 2 3 4	0 1 2 3 4



CONSUMER CONCERNS (continued)

Importance		Satisfaction	
0 =	Of no concern to me	0 =	Very dissatisfied
1 =	Not important	1 =	Dissatisfied
2 =	Somewhat important	2 =	Somewhat satisfied
3 =	Important	3 =	Satisfied
4 =	Very important	4 =	Very satisfied

<div>1 = Not important 2 = Somewhat important 3 = Important 4 = Very important</div> <div>1 = Dissatisfied 2 = Somewhat satisfied 3 = Satisfied 4 = Very satisfied</div>	How <u>important</u> is it to you that...[Show card]				How <u>satisfied</u> are you that ... [this is true; that this happens in your community] [Show card]					
	not		very		not		very			
Safety and Housing										
CC-5. ...you feel safe in your home and neighborhood.	0	1	2	3	4	0	1	2	3	4
CC-6. ...you can call for and get help in an emergency.	0	1	2	3	4	0	1	2	3	4
CC-7. ...affordable housing (both private and public) is available and accessible to people with all types of disabilities.	0	1	2	3	4	0	1	2	3	4
Public Services and Government										
CC-8. ...your tribal government and public services respond to the needs of American Indians with disabilities.	0	1	2	3	4	0	1	2	3	4
CC-9. ...Tribal buildings are accessible to native people with disabilities.	0	1	2	3	4	0	1	2	3	4
CC-10. ...Tribal and state agencies work together effectively to provide services for American Indians with disabilities.	0	1	2	3	4	0	1	2	3	4
CC-11. ...Public transportation to shopping, medical, and recreation centers is available to people with disabilities.	0	1	2	3	4	0	1	2	3	4
Health										
CC-12. ...good mental health care is available to American Indians with disabilities.	0	1	2	3	4	0	1	2	3	4
CC-13. ...health care professionals have adequate knowledge of American Indian cultures to provide effective and competent health care to American Indians.	0	1	2	3	4	0	1	2	3	4
CC-14. ...physical, speech, and occupational therapies are available on your reservation.	0	1	2	3	4	0	1	2	3	4



CONSUMER CONCERNS (continued)

Importance		Satisfaction	
0 =	Of no concern to me	0 =	Very dissatisfied
1 =	Not important	1 =	Dissatisfied
2 =	Somewhat important	2 =	Somewhat satisfied
3 =	Important	3 =	Satisfied
4 =	Very important	4 =	Very satisfied

Employment

CC-15. ...employment agencies and prospective employers focus on the strengths and abilities rather than the problems and difficulties/limitations of an applicant with a disability.

CC-16. ...adequate career counseling is available to all American Indians who have a disability.

CC-17. ...the job skills you learn are transferable to reservation employment.

CC-18. ...state and tribal vocational rehabilitation agencies provide self-employment opportunities to American Indians with disabilities on reservations.

CC-19. ...you have help getting a job in your community.

Social Service Providers

CC-20. ...social agencies inform you about benefits and services for which you qualify.

CC-21. ...American Indians with disabilities are actively involved in directing and operating programs designed to serve them.

CC-22. ...Independent Living Centers provide independent living services on reservations.

CC-23. ...Social service providers involve family members and extended family in your rehabilitation.

How important is it to you that... [Show card]		How satisfied are you that... [this is true; that this happens in your community] [Show card]	
not	very	not	very
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4
0	1 2 3 4	0	1 2 3 4



CONSUMER CONCERNS (continued)

Importance		Satisfaction	
0	= Of no concern to me	0	= Very dissatisfied
1	= Not important	1	= Dissatisfied
2	= Somewhat important	2	= Somewhat satisfied
3	= Important	3	= Satisfied
4	= Very important	4	= Very satisfied

Assistive Technology

CC-24. ...assistive devices (such as wheelchairs, braces, hearing aids, and so on) are available and affordable.

CC-25. ...financial assistance for examination and reasonably priced assistive and high tech devices (such as wheelchairs, braces, hearing aids, adaptive technology, and so on) are available to American Indians with disabilities.

CC-26. ...counselors work with consumers to find the right assistive or adaptive devices to help them function better.

Advocacy and Legal and Civil Rights

CC-27. ...you know your legal rights (regarding, for example, housing, employment, social services) as a reservation resident with a disability.

CC-28. ...Information about legal rights and self advocacy is available to American Indians with disabilities.

How important is it to you that ... [Show card]	How satisfied are you that ... [this is true; that this happens in your community] [Show card]			
	not	very	not	very
0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4



EDUCATIONAL INFORMATION

EI-1. What is the highest degree or diploma you have obtained?

- (1) ☐ High School diploma
(2) ☐ GED
(3) ☐ Trade or Vocational School certificate
(4) ☐ AA Degree
(5) ☐ Bachelor's Degree
(6) ☐ Master's Degree
(7) ☐ Other _____

EI-1a. [If less than high school] What is the highest grade you have completed?

EI-1b. [If some college but no degree] How many years of college? _____

EI-2. Would you like to increase your education?

- (1) ☐ Yes (2) ☐ No (3) ☐ Currently in school

EI-2a. [If yes] In what areas? _____

EI-2b. To what level? _____

[what kind of degree, certificate or license would you like to get?]



EMPLOYMENT INFORMATION

EM-1. Are you currently working for pay? (1) ☐ Yes (2) ☐ No

EM-1a. [If yes] What is your job? _____

EM-1b. [If yes] Are you satisfied with your job?
(1) ☐ Yes (2) ☐ No

EM-1c. [If yes] Are you employed (1) ☐ Full-Time
(2) ☐ Part-Time

EM-1d. [If no] Are you (1) ☐ Retired
(2) ☐ Retired on disability
(3) ☐ Unemployed because of disability
(4) ☐ Full-time student
(5) ☐ Part-time student
(6) ☐ Seasonal Worker
(7) ☐ Other _____

EM-2. What are your best job related skills? _____

EM-3. What type of job would you most like to have? _____

EM-4. Have you been looking for a job? (1) ☐ Yes (2) ☐ No

EM-4a. [If yes] How long have you been looking?
_____ Weeks _____ Months _____ Years

EM-4b. [If yes] Where have you been looking for a job? What agency(ies) are helping you? (for example, newspaper, job service, VR, and so on)

SOCIAL INFORMATION (INFORMAL SUPPORT SYSTEMS)

SO-1. Is there someone you can count on to give you help when you need it? (1) ☐ Yes [what relationship?] (2) ☐ No

SO-1a. Does this person provide you with:

- (1) ☐ Emotional support
- (2) ☐ Financial support
- (3) ☐ Help around the house?
- (4) ☐ Transportation
- (5) ☐ Something else? _____

SO-2. Does anyone live with you? (1) ☐ Yes (2) ☐ No

SO-2a. *[If yes]* Please tell me who lives with you now.
[indicate number of each]

	Number	Ages
(1) <input type="checkbox"/> Parent(s)	_____	_____
(2) <input type="checkbox"/> Brother(s)	_____	_____
(3) <input type="checkbox"/> Sister(s)	_____	_____
(4) <input type="checkbox"/> Grandparent(s)	_____	_____
(5) <input type="checkbox"/> Aunt(s)	_____	_____
(6) <input type="checkbox"/> Uncle(s)	_____	_____
(7) <input type="checkbox"/> Spouse	_____	_____
(8) <input type="checkbox"/> Grandchild(ren)	_____	_____
(9) <input type="checkbox"/> Niece(s)	_____	_____
(10) <input type="checkbox"/> Nephew(s)	_____	_____
(11) <input type="checkbox"/> Your child(ren)	_____	_____
(12) <input type="checkbox"/> Other	_____	_____
<i>[indicate, for example, friend or roommate]</i>		

SO-2b. Total number _____

SO-3. Do you see your relatives and friends as often as you want to?
(1) ☐ Yes (2) ☐ No

SO-4. Is where you live a: (1) ☐ House
(2) ☐ Apartment
(3) ☐ Homeless (No Housing)
(4) ☐ Other

SO-4a. *[If house]* Do you own or rent? (1) ☐ Own
(2) ☐ Rent
(3) ☐ Other

SO-5. How easy is it for you to get into, and to get around in, your home?

- (1) ☐ Very easy (2) ☐ easy
- (3) ☐ difficult (4) ☐ very difficult

SO-6. Do you have any kind of medical insurance or assistance?

- (1) ☐ Yes (2) ☐ No

SO-6a. *[If yes]* What kind? *[Check all that apply]*

- (1) ☐ Private (such as Blue Cross)
- (2) ☐ Medicaid
- (3) ☐ Medicare
- (4) ☐ VA
- (5) ☐ IHS
- (6) ☐ SSI, SSDI
- (7) ☐ Other _____

SO-6b. *[If no]* Why not? _____

REHAB MEDICAL FACILITY/HOSPITAL

RM-1. Did you go to a rehab medical facility or hospital for treatment of your disability?

(1) ☐ Yes (2) ☐ No [if No, please skip to next page]

RM-2. Did you get good support from your family when you were discharged from the rehab medical facility or hospital?

(1) ☐ Yes (2) ☐ No

RM-2a. If yes, explain the type of support your family gave you.

RM-2b. If no, what happened? (Please check appropriate responses that apply.)

(1) ☐ I lost what I had gained or learned during in-patient rehab therapies such as physical, mental, occupational, or speech. [Explain] _____

(2) Did this result in becoming more dependent on your family for your activities of daily living (bathing, dressing, eating, and getting around the house).

(1) ☐ Yes (2) ☐ No

(3) ☐ I was sent to a nursing home or a similar facility so I can get some personal care. [Explain] _____

RM-3. Upon discharge from the rehab medical facility or hospital [check those that apply]

(1) ☐ My home was made accessible so I can live independently

(2) ☐ My counselor visited me within ____ month(s) of discharge to find out what types of service I needed.

<input type="checkbox"/> one	<input type="checkbox"/> seven
<input type="checkbox"/> two	<input type="checkbox"/> eight
<input type="checkbox"/> three	<input type="checkbox"/> nine
<input type="checkbox"/> four	<input type="checkbox"/> ten
<input type="checkbox"/> five	<input type="checkbox"/> eleven
<input type="checkbox"/> six	<input type="checkbox"/> 1 year

(3) ☐ Follow-up was done through mail, a phone call, or home visit by:

<input type="checkbox"/> My doctor
<input type="checkbox"/> Social worker
<input type="checkbox"/> IL or VR counselor
<input type="checkbox"/> CHR
<input type="checkbox"/> Peer counselor
<input type="checkbox"/> No follow-up

(4) ☐ I was left without any resources for services for me to apply for.

PERSONAL ASSISTANCE

Personal assistance means one human being assists another person with a disability to do something the person with a disability could not do for himself/herself. People get assistance with various things. A few examples are getting in or out of bed, dressing, eating, bathing, cooking, shopping, laundry, transportation, or reading. Personal assistance has been a useful resource for people with disabilities to help realize their rights. Different people get assistance in different ways and some ways work better for certain people.

PA-1. Do you have a person that helps you do things such as those mentioned above? (1) ☐ Yes (2) ☐ No

PA-2. What do you call that person? _____

PA-3. Please describe some of the activities which [the person named above] does for you. _____

PA-4. How did you get the help of [the person named above]? _____

PA-5. What personal life goal did you hope to meet by using this personal assistance? _____

PA-6. Can you describe a situation in which this personal assistance worked well for you? _____

PA-7. Can you describe a situation in which this personal assistance did not work well for you? _____

PA-8. Who would you prefer to provide personal assistance?

- (1) ☐ Family or extended family member volunteer
(2) ☐ Family or extended family member paid by government money
(3) ☐ Non family member paid by government money
(4) ☐ Other [please describe] _____

PA-9. For a family member assisting you, what difference would it make if they were paid? _____

PA-10. What kind of services would you need for paid personal assistance to work under conditions (rural, reservation, or urban) where you live? [After pause, prompt with phrases such as "transportation for the assistant?" or "family commitment?"] _____

PA-11. If there were money to pay an assistant, to whom should the funder make out the check?
(1) ☐ Person using the service
(2) ☐ Person providing the service
(3) ☐ Head of the family
(4) ☐ An agency to manage the service
(5) ☐ Other [please specify] _____

PA-12. If a family member were paid for personal assistance, what do you think would change between you and the paid family member? _____

PA-13. If the paid assistant were not a family member, what do you think would change between you and other family members? _____

PA-14. What would you recommend as a way to improve assistance that you might get? _____

CN-4. Do you have any additional comments or suggestions?

(1) ☐ Yes (2) ☐ No

(1) ☐ Yes (2) ☐ No

CN-5. May I give your name (and phone number, if any) to a VR/IL counselor to find out if you are eligible for vocational rehabilitation or independent living services?

(1) ☐ Yes (2) ☐ No

Go back to page 1 and record ending time of interview
Be sure to have interviewee sign Interviewee Billing Statement
Don't forget to fill out the next page after you leave!

**INTERVIEWER JUDGEMENT SCALES***[Circle one for each scale]*

IJ-1. To what degree did the respondent appear to understand the questions?

	Not at all	Sometimes	All the time
	0	1 2 3 4 5 6 7 8 9	

IJ-2. To what degree did you feel the respondent was being open and/or honest with you?

	Not at all	Sometimes	All the time
	0	1 2 3 4 5 6 7 8 9	

**INTERVIEWER COMMENTS**

IJ-3. Please record the final status of the interview *[Check one]*

- (1) ☐ interview complete
(2) ☐ interview not completed *[check reason below]*

- (a) ☐ respondent not at home after 3 visits
(b) ☐ refusal *[explain]*

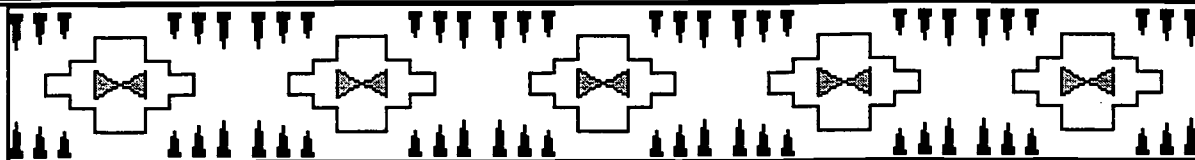
- (c) ☐ breakoff, partial data *[note circumstances]*

- (d) ☐ language barrier *[note circumstances]*

- (e) Other *[specify]*

Appendix C

Explaining the Study



AMERICAN INDIAN REHABILITATION RESEARCH AND TRAINING CENTER
NORTHERN ARIZONA UNIVERSITY

*VR Independent Living Counselor Effects on Independent Living Outcomes
for American Indians with Disabilities (Project R-40)*

EXPLAINING THE STUDY

Purpose

The purpose of this study is to understand the needs of American Indians who may have problems which limit their ability to independently carry out daily activities, such as walking, talking, cooking, eating, bathing, or shopping.

Procedure

You are being asked to participate in a meeting that should take approximately 3 to 4 hours. You will receive \$20 in appreciation for your time. You will be asked about what problems are most important to you. We will use this information to develop a questionnaire so that we can interview other consumers.

Benefits

This information will help us train Independent Living & Vocational Rehabilitation counselors so they can do a better job of providing services to American Indians who have severe disabilities. You will also have the opportunity to attend a public meeting where the results of the study will be presented and your questions answered.

- ❖ *Purpose* To better understand the needs and interests of American Indians with severe disabilities
- ❖ *Confidentiality* Your name will not be linked to any specific suggestions you make.
- ❖ *Voluntary* You may refuse to answer any question, and may leave the meeting at any time.
- ❖ *Benefits* Community meeting about how to improve services.

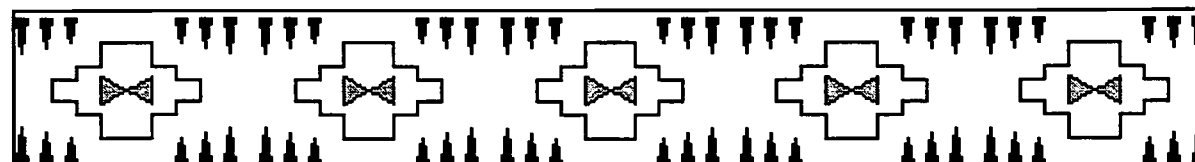
For more information, contact:

Tonilisa Nezz (Navajo)
PO Box 920
Fort Defiance, AZ 86504
520-729-5986

or

Priscilla Sanderson (Navajo), 520-523-5581*
Julie Anna Clay (Omaha), 520-523-1340*
Robert Schacht, 520-523-1342*

*Outside of Flagstaff, AZ: call 1-800-553-0714



Appendix D

Community Meeting Agendas and Maps

March 25, 1996

LETTER OF INVITATION

The American Indian Rehabilitation Research and Training Center (AIRRTC) at Northern Arizona University invites you to a community meeting to discuss the preliminary results of the Consumer Concerns interview that were conducted in Arizona this past year by Ms. Shannon Pierce.

The purpose on the Consumer Concerns interview was to understand the needs of American Indians who may have problems which limit their ability to independently carry out daily activities, such as walking, talking, cooking, eating, bathing, or shopping. The results have been compiled and a preliminary report will be distributed at the community meeting. The purpose of the community meeting is to receive your feedback and input on the preliminary results which will be recorded and taken into consideration for the Final Report.

There will be two community meetings in Arizona, one in Phoenix and the other in Tucson. Enclosed are fliers, please invite other community members with disabilities and services providers to attend the meeting.

We have been informed that the community buildings are wheelchair accessible. If you need a sign language interpreter, Braille or enlarged printed materials, or other accessibility needs, please inform us by April 1, 1996 by calling Ms. Priscilla Sanderson or Dr. Robert Schacht at 1-800-553-0714.

We look forward to meeting you at the Arizona Community Meetings in Phoenix or Tucson.

Ms. Priscilla Lansing Sanderson
AIRRTC Director

Dr. Robert M. Schacht
AIRRTC Research Specialist Sr.

Ms. Julie Anna Clay
AIRRTC Research Specialist

AMERICAN INDIAN REHABILITATION RESEARCH AND TRAINING CENTER
(AIRRTC)

Institute for Human Development, Northern Arizona University

COMMUNITY MEETING AGENDA

Navajo Chapter House
Ramah, New Mexico
January 25, 1996
10:00 am - 3:00 pm

Community Meeting On Preliminary Results Of Research Project: Vocational Rehabilitation
(VR) Independent Living Counselors Effects on Independent Living Outcomes for
American Indians with Disabilities.

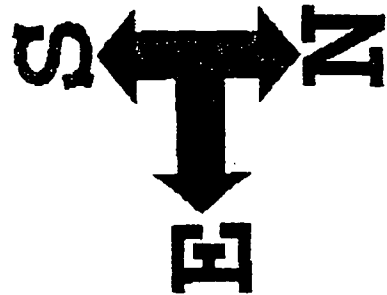
Moderator: Ms. Julie Anna Clay, Research Specialist, AIRRTC

10:00 am *Welcome*
Ms. Priscilla Lansing Sanderson, Director, AIRRTC
10:05 am *Overview of Research Project*
Ms. Priscilla Lansing Sanderson
10:30 am *Experiences of NM Interviewer*
Ms. Tonilisa Nezz, Research Assistant, AIRRTC
11:00 am *Summary of Results*
Dr. Robert Schacht, Research Specialist, Sr., AIRRTC
12:00 pm *Lunch will be provided*
1:00 pm **Feedback on Consumer Concerns "Open Mike"*
2:30 pm *Closing Remarks*
Ms. Priscilla Lansing Sanderson
Dr. Robert Schacht
Ms. Tonilisa Nez
Ms. Julie Anna Clay
3:00 pm *Adjourn*

NOTE

For Transportation Assistance to the Community Meeting Call:
Zee Corporation and ask for Mr. Larry Aflen at (505) 782-2898

* Concerned community members, American Indians with disabilities, program directors,
service providers, and tribal leaders are encouraged to comment on the preliminary results
of the study.



From Gallup, N.M. South on
State 602 then East on Hwy. 53
to Hwy. 125 South to Ramah
Navajo Chapter House.
If you reach Pine Hill Market
you've gone to far.

Ramah
Navajo
Chapter
House

Pine Hill Market

Hwy. 125

Lewis
Trading
Post

To El Morro

Ramah
Community

Hwy. 53

Zuni, New Mexico

State 602

BEST COPY AVAILABLE

Gallup, New Mexico

AMERICAN INDIAN REHABILITATION RESEARCH AND TRAINING CENTER
(AIRRTC)

Institute for Human Development, Northern Arizona University

COMMUNITY MEETING AGENDA

Elderly Home Care Center

Crownpoint, New Mexico

January 26, 1996

10:00 am - 3:00 pm

Community Meeting On Preliminary Results Of Research Project: Vocational Rehabilitation
(VR) Independent Living Counselors Effects on Independent Living Outcomes for
American Indians with Disabilities.

Moderator: Ms. Julie Anna Clay, Research Specialist, AIRRTC

10:00 am *Welcome*

Ms. Priscilla Lansing Sanderson, Director, AIRRTC

10:05 am *Overview of Research Project*

Ms. Priscilla Lansing Sanderson

10:30 am *Experiences of NM Interviewer*

Ms. Tonilisa Nezz, Research Assistant, AIRRTC

11:00 am *Summary of Results*

Dr. Robert Schacht, Research Specialist, Sr., AIRRTC

12:00 pm *Lunch will be provided*

1:00 pm **Feedback on Consumer Concerns "Open Mike"*

2:30 pm *Closing Remarks*

Ms. Priscilla Lansing Sanderson

Dr. Robert Schacht

Ms. Tonilisa Nez

Ms. Julie Anna Clay

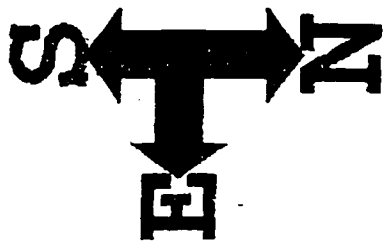
3:00 pm *Adjourn*

NOTE

For Transportation Assistance to the Community Meeting Call:
Zee Corporation and ask for Mr. Larry Aflen at (505) 782-2898

* Concerned community members, American Indians with disabilities, program directors,
service providers, and tribal leaders are encouraged to comment on the preliminary results
of the study.

From Gallup, N.M. North on
State Rd. 666, East on
Navajo Nation Rd. 9, to
Crownpoint, N.M.,
South on Street C, East on
Street A, to the Elderly
Home Care Center.



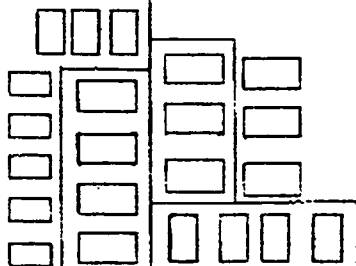
Parking



Elderly Home
Care Center



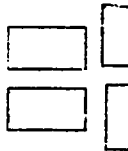
Street A



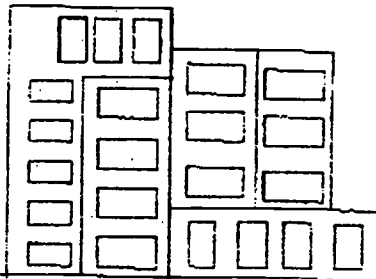
Crownpoint
Institute
of
Tech

Police St.

Street C



Crownpoint
High
School



Basbas

Navajo Rd. 9

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